

**Centre for Population Health Research  
Faculty of Health Sciences**

**Blinding eye disease in Western Australia: perspectives on data  
integration**

**Antony Clark**

**This thesis is presented for the Degree of  
Doctor of Philosophy  
of  
Curtin University**

**November 2014**

*To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgment has been made.*

*This thesis contains no material that has been accepted for the award of any other degree or diploma in any university.*

Signed:

A handwritten signature in black ink, appearing to be 'Antony Clark', written over a horizontal line.

Date: 8 November 2014

Antony Clark



## Thesis summary

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This thesis explores the use of large integrated health administrative datasets and other epidemiologic methods to evaluate blindness and the safety, quality and outcomes of eye care provided for three major blinding eye diseases (cataract, diabetic retinopathy and age-related macular degeneration (ARMD)) in Western Australia (WA). The WA population is ideal for population-based research that is representative of the wider Australian context. Trends and outcomes of cataract surgery in WA were explored using large integrated hospital administrative datasets. Major changes in cataract surgery technique have occurred over a 21-year period in WA, culminating in the introduction of same-day phacoemulsification surgery and an exponential rise in surgical volume. The impact of serious complications of cataract surgery on patient quality of life is significant. Fortunately despite increased cataract surgery volume surgical safety has improved and the trend in major serious sight-threatening complications (i.e. retinal detachment, intra-ocular lens dislocation, endophthalmitis, wound dehiscence and dropped nucleus) has declined by nearly 50% during each 5-year period since 1980. Retinal detachments are the most common sight-threatening complication where males, younger patients and those having complicated cataract surgery requiring anterior vitrectomy were at higher risk. Cataract surgery requiring anterior vitrectomy is a major risk factor for all serious sight-threatening complications. The number of surgeries requiring anterior vitrectomy increased when phacoemulsification was first introduced in WA but thereafter declined. Major risk factors were male gender, age <50 years or >80 years, and surgery in public hospitals.

Limitations in administrative databases lead to the exploration of how alternative epidemiological methods and data sources may be brought together to provide an alternative view on outcomes. A post-marketing surveillance study combined integrated hospital administrative data with surgeon logbooks and databases to examine the safety of anti-vascular endothelial growth factor inhibitors for the treatment of ARMD. It found the risk of stroke and gastrointestinal bleeding events is low while myocardial infarctions were over twice the community rate. This increased rate equates to a marginal increase in

the absolute risk for myocardial infarct. This marginal increase must be weighed against the significant potential to avoid blindness with treatment, which on an individual at least, may be acceptable.

Blindness is poorly coded in hospital administrative datasets. The epidemiology of blinding eye disease study (EBEDS) demonstrated that the WA blind register is relatively precise in its diagnostic accuracy for the major cause of blindness and moderately good in accurately ascribing blindness. However, a unique capture-recapture technique used to calculate the prevalence of blindness in WA demonstrated over half the blind population is unknown to government and blind service providers. This population represents an important group of vulnerable people who have increased mortality, poorer quality of life and greater use of health services than those who are not blind.

The remote Aboriginal Australian population are vulnerable with poor access to health care and also poorly represented in hospital administrative data. A unique Goldfields eye health survey allowed the study of the major causes of vision loss in remote eastern Goldfields communities in WA over a 12-year period. The major causes of vision loss are preventable or treatable, and diabetes has a major association. Despite this, screening for diabetic retinopathy is very poor and highlights deficiencies in community screening in these vulnerable remote populations.

A national Australian survey of general practitioners (GPs), optometrists and ophthalmologists was conducted to ascertain current diabetic retinopathy screening and management practices. This showed an improvement in diabetic retinopathy screening and management since the publication of National Health and Medical Research Council guidelines. Optometrists are the most motivated to participate in community screening for diabetic retinopathy yet have the least knowledge compared to ophthalmologists and GPs. GPs report major barriers to performing dilated retinal examinations including lack of confidence in detecting signs; while optometrists are the better equipped, further education is recommended if they are to take on community screening.

## Acknowledgements

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And finally to David, I can't thank you enough. You've kept me going!

## Research output from this thesis

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### Published manuscripts

1. **Clark A**, Ng JQ, Morlet N, Mahendran P, Tropiano E, Spilsbury K, Preen DB, Semmens JB. **Quality of life after postoperative endophthalmitis.** *Clinical and Experimental Ophthalmology* 2008; 36(6):526-531.
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1. Curtin University Postgraduate Scholarship (CUPS), *Curtin University* 2008-2009; \$40,000.

## **Statement of contribution of others**

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This thesis originated from work that has arisen through multiple projects under the theme of blinding eye diseases in WA. The major bulk comprises the Complications of Cataract Surgery Project. This NHMRC funded project (grant numbers 110250 and 303114) was initially conceived by my supervisors A/Professor Nigel Morlet and Professor James Semmens, and Dr Jonathon Ng as an evolution of the Endophthalmitis Population Study of Western Australia (EPSWA); a project originally conducted from the WA Safety and Quality of Surgical Care Project. I lead the study from January 2007 including the project management, data collection, data validation, data analysis, and dissemination of research findings. All manuscripts originating from this work I authored with co-author input from my supervisors and Professor David Preen from the School of Population Health, The University of Western Australia (UWA). This work also supported the application for a National Eye Health Initiative grant from the Australian government to fund the translational phase of this project – the implementation of an electronic cataract surgery register. I wrote the application for this grant, which was successful in securing \$163,883 in funding.

The quality of life after post-operative endophthalmitis survey was conducted as part of EPSWA. My supervisors Dr Ng and Clin Prof Morlet initially conceived the survey, while my co-authors Priya Mahendran and Elizabeth Tropiano administered the quality of life questionnaire. I conducted the data collation, data analysis, manuscript preparation and dissemination of the survey findings.

The Vascular Endothelial Growth Factor Inhibitors and Cardiovascular Events (VICE) study was undertaken through UWA. In this study I assisted in the research design and grant application; wrote the project ethics application and data linkage requests; developed the database used for primary data collection; co-ordinated and undertook primary data collection with the assistance of my co-authors (Dr Charlotte McKnight and Dr Wayne Reynolds); assisted my co-authors with data analysis, interpretation and preparation of the final manuscript.



My supervisors Prof Semmens and Clin Prof Morlet; and Prof Morgan originally conceived the Epidemiology of Blinding Eye Diseases project idea. The Eye Surgery Foundation funded the project. Ms Julie Crewe was overall project supervisor and was responsible for the majority of the study conduct, data analysis and manuscript preparation. I was significantly involved in the clinical validation clinics to validate the blind register, assisted and provided advice on data analysis and input into manuscript preparation and final approval prior to submission.


The diabetic retinopathy and major causes of vision loss in aboriginals from remote WA was a project I worked on closely with my co-authors Professor William Morgan and Professor Dao Yi Yu at the Centre for Ophthalmology and Vision Sciences, The University of Western Australia. The data that comprised the paper arose from clinical work Professor Morgan undertook over a 12-year period collecting clinical data pertaining to eye clinics he performed in the region for the Eastern Goldfields eye health survey. I played the lead role in data validation, data analysis and manuscript preparation.

The diabetic retinopathy screening and management practices survey was administered through the Centre for Health Services Research within the School of Population Health, UWA; under the supervision of Professor David Preen. I lead the project having the primary role in research design, development of the survey tool, and co-ordination of the mail-out process. I was assisted by my co-authors, Dr Joshua Yuen and Dr Daniel Ting, in data entry and manuscript preparation. In all manuscripts I made a significant contribution to the data analysis and manuscript preparation.

Signed:



Dr. Antony Clark (Candidate)



Professor James B Semmens (Supervisor)

Date: 8 November 2014

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## Abbreviations

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ABS	Australian Bureau of Statistics
ARMD	Age-related macular degeneration
ABWA	The Association for the Blind of Western Australia
CI	Confidence interval
CNV	Choroidal neovascularisation
ECCE	Extracapsular cataract extraction
EBEDS	The epidemiology of blinding eye disease study
EHR	Electronic health record
HMDC	Hospital morbidity data collection
HR	Hazards ratio
ICD	International classification of diseases
ICCE	Intracapsular cataract extraction
IOL	Intraocular lens
IRR	Incidence rate ratio
OR	Odds ratio
ORLS	Oxford record linkage study
PHRN	Population health research network
PY	Person-years
UK	United Kingdom
US	United States of America
VEGF	Vascular endothelial growth factor inhibitor
WA	Western Australia
WADLS	Western Australian Data Linkage System

## **Exegesis**

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### **Explanatory overview**

Vision loss and blindness presents a significant health concern. It ranks as the seventh leading cause of loss of wellbeing,<sup>1</sup> and is associated with greater social dependence, increased morbidity (including increased risk of falls)<sup>2,3</sup> and poorer quality of life.<sup>4-7</sup> It is also costly, costing Australia AU\$9.85 billion in 2004.<sup>8</sup> Vision problems affect over half of the Australian population and vision impairment or blindness affects approximately half a million Australians.<sup>9,10</sup> Age is the single most important risk factor for vision impairment and blindness: the risk increases threefold for each decade over the age of 40. In Australia 39% of people over 90yrs of age are vision impaired.<sup>10</sup> Future projections for an ageing and growing population predict the number of people with vision loss in Australia will double by 2020.<sup>10,11</sup>

Blinding eye disease is a Australian national health priority.<sup>12</sup> Over 75% of cases of blindness and vision loss in Australia are avoidable - the major causes being (after refractive error) ARMD, cataract, glaucoma and diabetic retinopathy.<sup>13-15</sup> Addressing these problems requires an understanding of who are affected and ophthalmic care they are provided. In particular, we need to understand how this care is being delivered and utilised, who are the vulnerable or at risk populations, and what are the outcomes of those services we provide. Armed with this knowledge we can then devise and implement strategies for improvement.

Health services research examines the relationship between the provision, effectiveness and efficient use of health services and the health needs of the population. It has a broad scope that covers multiple disciplines and research methodologies.<sup>16</sup> The Institute of Medicine Committee on Quality Health Care in America state health systems should be able to deliver health services that are safe, effective, patient-centred, timely, efficient and equitable.<sup>17</sup> Measuring the ability of a health system to deliver on these goals is a key part of health services research and forms the basis of this thesis as it pertains to blindness and blinding eye disease in WA. In addition to the epidemiology of blindness, three of the blinding eye diseases are a particular focus for this thesis.

- i. *Cataract* – Is a major focus. Ready and timely access to modern cataract surgery facilities in WA means cataracts are rarely blinding though the

complications of surgery can be. While cataract surgery is very safe, over 13,000 cataract operations are performed each year in WA so even rare complications have the potential to produce significant morbidity in the community.

- ii. *Diabetic retinopathy* - Diabetes prevalence continues to grow across most developed countries and the burden of diabetic retinopathy expected to follow. Diabetic retinopathy, if not treated, causes permanent loss of vision and eventually blindness due to macular oedema, retinal neovascularization, retinal ischemia or tractional retinal detachment. Prevention of vision loss from diabetic retinopathy relies on early detection and early treatment that is supported by comprehensive community screening. This is particularly so in remote and Aboriginal communities where rates of diabetes are high and access to health care is poor.
- iii. *Age-related macular degeneration (ARMD)* - ARMD is the leading cause of irreversible blindness in elderly population. There are two forms characterised by predominantly photoreceptor atrophy ('dry') and gradual vision loss, or the development of choroidal neovascularisation (CNV) ('wet') and sudden profound vision loss. Prior to 2005 an effective treatment for wet ARMD was not available and patients simply went blind and little could be done to alter the progression of disease. The widespread introduction of the vascular endothelial growth factor inhibitors (anti-VEGF) in 2005 revolutionized the treatment and prognosis for this disease.<sup>18,19</sup> The treatment has been taken up with great zeal in WA, although concerns still persist regarding the systemic safety of anti-VEGF agents. There is a distinct need for post-marketing surveillance for assessing its safety.

# **Aims and objectives**

The primary goal was to evaluate the epidemiology of blindness and particularly the state of ophthalmic care in WA pertaining to important aspects of important potentially blinding eye diseases i.e. cataract, diabetic retinopathy, and ARMD. An over-arching theme was to also explore how this goal may be achieved utilising existing data sources available for health services research. While hospital administrative databases offer the power of large numbers that are truly population-based they lack clinical detail to allow in-depth study of ophthalmic diseases and health outcomes. For this, alternative data sources and methodologies such as clinical surveys and registries are explored.

The following outlines the specific aims and objectives for this thesis.

## **Aim 1. Establish how representative the WA population is of the Australian population**

Objective 1. Compare the WA population key socio-demographic and health economic indicators to the Australian national average and individual state and territory averages.

## **Aim 2. Use linked hospital administrative data to evaluate cataract surgery complications and outcomes in WA**

Objective 2. Measure the rates and trends of major sight-threatening complications of cataract surgery in Western Australia.

Objective 3. Evaluate the major risk factors for pseudophakic retinal detachment after phacoemulsification

Objective 4. Describe the trends in complicated cataract surgery and calculate the increased risk of adverse outcomes following complicated cataract surgery.

Objective 5. Measure the impact of a major blinding complication of cataract surgery (e.g. postoperative endophthalmitis) on patient reported quality of life.



**Aim 3. Use clinical registers to supplement hospital administrative data in assessing the safety of vascular endothelial growth factor inhibitors (anti-VEGF) for ARMD.**

- Objective 6. Determine whether treatment with anti-VEGF for wet ARMD increases the risk of hospitalisation or death for cerebrovascular or cardiovascular events.
- Objective 7. Evaluate whether an association exists between the cumulative dose of intravitreal ranibizumab or bevacizumab and risk of cerebrovascular or cardiovascular events for patients with wet AMD.

**Aim 4. Use a blind registry and capture-recapture techniques to describe the epidemiology of blindness in WA.**

- Objective 8. Validate the clinical diagnosis and cause of blindness in the existing WA blind registry.
- Objective 9. Use capture-recapture techniques to validate existing population estimates of blindness in WA.
- Objective 10. Integrate the blind registry with the WADLS to determine associations between blindness and cause of death, co-morbidities and health services utilization.

**Aim 5. Use an electronic clinical register to evaluate the causes of blindness and the impact of diabetes on remote Aboriginal communities in WA.**

- Objective 11. Determine the major causes of vision loss in remote Aboriginal communities.
- Objective 12. Determine the prevalence of diabetic retinopathy among diabetic Aboriginal patients in remote Aboriginal WA communities.
- Objective 13. Evaluate the adequacy of eye screening for Aboriginals with diabetes.

**Aim 6. Use clinical survey methods to evaluate diabetic retinopathy screening and management practices.**

Objective 14. Describe diabetic retinopathy screening and management practices of Australian GPs, Ophthalmologists and Optometrists.

Objective 15. Identify barriers in adhering to recommended diabetic retinopathy screening and management practices experienced by eye care providers and factors associated with these.

Objective 16. Evaluate the long-term impact of the 1997 NHMRC Diabetic Retinopathy Management Guidelines on improving diabetic retinopathy screening and management practices amongst eye care providers.

# Thesis overview

This thesis comprises the summation of a large body of work, undertaken over the course of several projects, to address the thesis aims and objectives. It is divided into 4 major chapters supported by 15 papers published in the peer-reviewed literature (including 6 where the candidate was first author).

Chapter 1 begins with a literature review. A description of the WADLS and how administrative data are used for health services and ophthalmic research is explored. This chapter forms the basis of a review paper currently under consideration for publication in Survey of Ophthalmology (Appendix 5).

Chapter 2 addresses the first aim to evaluate the representativeness of the WA population of the wider-Australian context, therein supporting the external validity of findings presented in subsequent chapters of this thesis. (1 paper)

Chapter 3 addresses the second aim to describe sight-threatening complications of cataract surgery using administrative databases. In doing so, this chapter demonstrates how these datasets support research in ophthalmic trends and outcomes. (3 papers)

Chapter 4 addresses the final aims and explores how other data sources may value-add to research arising from administrative databases. This is achieved across five themes – the epidemiology of blindness, post-marketing surveillance, vulnerable and isolated populations, quality of life and clinician knowledge and practices. The risk of cardiovascular events after anti-VEGF treatment for ARMD is estimated in one paper. The epidemiology of blindness in WA, including quality of life for blind people, is described across five papers. Trends in diabetic retinopathy and the causes of vision loss in Aboriginals from the remote Eastern Goldfields region of WA are described in another paper. The impact of postoperative endophthalmitis after cataract surgery on quality of life is described in one paper. Knowledge surrounding diabetic retinopathy screening guidelines and current management practices of health professionals involved in eye care (ophthalmologists, optometrist and GPs) are described in three papers. (10 papers)

## Chapter 1

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# **The 'big data' revolution: a review of large administrative databases, data integration and ophthalmic research**

## 1.1. Introduction

*[This Chapter forms the basis for a review paper under review for publication in Survey of Ophthalmology (Appendix 5)]*

“Big data” is a relatively new concept that describes data so large and complex that it exceeds the storage or computing capacity of most systems to perform timely and accurate analyses.<sup>20,21</sup> Health generates huge amounts of data from a wide array of sources such as electronic health records (EHR), health insurance claims, and even smart phone applications that monitor patient health. It is the subject of intense interest as industry and researchers alike realize the huge potential in extracting value from existing data systems. The ‘big data revolution’ is being increasingly supported by national governments, who are funding initiatives designed to develop and capitalize on big data.<sup>21,22</sup>

Even before the big data revolution, health researchers have long recognized the value in large administrative databases.<sup>23</sup> The last decade has seen a dramatic increase in the their use for ophthalmic research.<sup>24,25</sup> These databases contain a wealth of information that can now be accessed in a timely and cost-efficient manner due to advances in computing power and the development of new analytical methodologies.<sup>26</sup> These advances have also facilitated data linkage or integration processes that offer greater utility over using individual databases for health research e.g. linking pharmaceutical claims data to hospital discharge data allows study of health outcomes associated with medication use. It promises the potential for more, almost limitless, amounts of data available for research.

The health research landscape in Australia has recognised this revolution and there is now an imperative to develop and capitalise on our available health administrative data through data integration processes.

In this chapter, large administrative databases and data linkage systems in place today will be reviewed including their benefits and limitations for health research, and how they have been used for research in ophthalmology.

## **1.2. Administrative data and data integration**

### **1.2.1. Administrative data characteristics**

Administrative databases used in health research are pre-existing datasets whose primary purpose is the storage of information routinely collected from the point of service, usually for billing purposes e.g. hospital insurance claims information and pharmaceutical billing data. The variables typically recorded range widely but generally include: a patient specific identification number, demographic details (e.g. name, sex, date of birth, and address) and limited clinical data (e.g. diagnostic/procedural codes in health insurance claims data or drug codes in pharmaceutical claims data). These database are normally very large, cover large defined populations within a given health jurisdiction, and span years if not decades of service.

Clinical registries are different to administrative databases; they are designed to collate detailed clinical information, usually for quality assurance and clinical audit. Only a few truly population-based ophthalmic registries currently exist, though this number is increasing. Those most notable are the cataract surgery,<sup>27,28</sup> and corneal transplant registries.<sup>29-31</sup> These registers are powerful tools for health research due to the level of detailed clinical information they contain that current administrative databases simply cannot match.

### **1.2.2. Data integration**

Data integration, or data linkage, is defined as the "bringing together from two or more different sources, data that relate to the same individual, family, place or event".<sup>32</sup> The concept was most eloquently described by Dr Halbert L Dunn in 1946 when he proposed the concept of a "Book of life".<sup>33</sup> Such a book is comprised of records from significant events in a person's life - their birth, education, marriage, divorce, illness and finally their death. He suggested records relating to these events could be collated to form a person's personal file and that collating these files on a population-wide basis would be useful in generating knowledge in a wide range of areas, particularly for health and welfare organisations. He defined this process as 'record linkage' - a term that has evolved into the more broadly encompassing term of 'data integration' to



**Figure 1-1** Dr Halbert Dunn  
(1896 - 1975)

recognise that information can come from sources beyond our old fashioned concepts of 'records' e.g. geospatial information systems.

#### *Data linkage techniques*

The linkage of two or more datasets requires identifiers that are common to all datasets.<sup>34,35</sup> Such identifiers may be unique (e.g. a patients insurance number), or partial (e.g names, date of birth, gender, place of birth, postcode etc) and are matched using any of three general techniques:

- i. Unique matching (deterministic matching) - data are linked according to unique identifiers e.g., health insurance number. This would be the most expeditious way to link data yet few datasets share a common identifier limiting the potential data that can be linked. In addition, due to the potential for recording errors this method may only identify 80-85% of true matches.<sup>35</sup>
- ii. Fuzzy matching - data are linked according to partial identifiers (usually multiple). This technique allows for a margin for error by linking records that are almost the same. The computer will either present a choice of matches to the user or will rely on a scoring system to confirm a match. This usually identifies 85-90% of true matches.<sup>35</sup>
- iii. Probabilistic matching - the decision regarding a match is made using decision rules that are built into a software package. These are based on the probability that two records are from different people given they have the same identifiers. The probabilities are then aggregated to form a score and a link is confirmed if a predefined threshold is reached. This typically identifies 95-99% of true matches with a 1-2% false positive rate.<sup>34-36</sup>

### **1.2.3. Benefits and limitations for health research**

Since research arising from administrative data is observational by nature there has been some skepticism regarding its value.<sup>37,38</sup> This is compounded by the heavy emphasis on randomized controlled trials (RCT) as the 'gold standard' for evaluating treatment, which ignores the limitations inherent in RCT methodology. RCTs do not reflect real-life community practice, leaving clinicians to use their judgment in extrapolating findings from trials that relate to a highly selected patient that is seldom encountered. Observational studies using large databases can complement RCTs by going some way towards addressing their limitations.<sup>38</sup> Their large size provides whole-population capture; thereby avoiding non-representative samples and selection bias, which may occur in randomized trials. They measure the true effectiveness of an intervention that is based on actual 'real world' practice unlike the highly controlled environment in RCTs. They are also better powered to study rare events and small effect sizes due to very large sample sizes, and the typically long time span covered by many databases enables long-term events to be examined. Recall bias and bias related to non-participation and loss to follow-up is minimized since all eligible people are included and, because these databases are primarily created for administrative purposes, individual patient consent is usually not required or warranted.<sup>32,39</sup>

The advantages and social benefits of research arising from large administrative data and data linkage systems over traditional research methods are significant and include:

- i. decreased cost of research: using existing data is a relatively cheap and effective alternative to primary data collection.<sup>34,39</sup>
- ii. increased efficiency of research: access to existing clinical information vastly reduces time compared to studies requiring primary data collection. This is particularly important when assessing safety of new treatments such as post-marketing surveillance of new drugs.<sup>40</sup>
- iii. conservation of patient privacy: the privacy of individual patients is conserved since it is usually not necessary for personal identifiers to



be provided to researchers.<sup>41</sup> Using de-identified administrative databases also conserves the privacy of all patients, regardless of whether they would have given consent. A consent-based approach conserves the privacy only of those who do not participate, usually at a cost of making the research impractical.<sup>42</sup>

- iv. adding value to existing information assets: integrating datasets generates a greater return on investment in routine administrative data sets and facilitates quality improvement of data through the linkage process.<sup>43</sup>

Limitations of studies using administrative data surround the use of data whose primary purpose is not for research.<sup>24,25,44</sup> The researcher should be cognisant of how the data was collected and coded. The first hurdle relies on the patient with a particular condition seeking care – if it is not serious enough to warrant seeking health care it will not be recorded and cannot be studied. There also needs to be a code attached to the condition or procedure of interest (usually International Classification of Diseases codes (ICD) e.g. ICD-10) and any additional uncoded clinical data cannot be studied. Codes may not be specific enough to allow more detailed study e.g. ‘glaucoma’ rather than ‘pigment dispersion glaucoma’; and may not necessarily indicate severity of a condition. Establishing laterality to a particular eye is a major problem since many datasets historically did not record this information and may limit investigation of adverse events.

Data quality and completeness will tend to vary across databases and variables being studied. Some errors are less likely to occur e.g. coding for primary surgical procedures; while others have been shown to be prevalent e.g. omitted coding for secondary diagnoses.<sup>25,44,45</sup> Databases may also change over time with changes in codes and the addition or deletion of variables. The way data is generated or collated may also vary between datasets and with time.<sup>44</sup>

It is essential that the researcher intimately understand how their data was generated and how it may have evolved over time. A close working relationship between researcher and data custodian is essential if errors in analysis and interpretation are to be avoided. Validation studies with chart review can help

quantify the size of these issues within any given data collection e.g. diabetic macular edema,<sup>46</sup> acute glaucoma,<sup>47</sup> eye drop therapy in glaucoma patients,<sup>48,49</sup> and endophthalmitis.<sup>50</sup>

Care must also be taken when calculating incidence/prevalence or generalizing results to the wider population since many databases contain a limited subset of the population that is unlikely to be representative of the whole. For example, the US Medicare database only includes those older than 65 years or disabled or poor; while health insurance company claims data is limited to those who can afford health insurance and omits vulnerable lower socioeconomic groups and racial minorities without insurance who are more likely to need care. The limited coverage of insurance databases also means loss to follow-up can be an issue when patients move in and out of the insurance organization. Conversely databases in jurisdictions with universal health care, and particularly data linkage systems, are truly population-based and so are readily generalized with very little loss to follow-up and can offer true measures of incidence and prevalence.

Finally, analysis of these databases should take into account the risk of confounding due to comorbidity, socio-demographic factors and effect modification.<sup>24,25</sup> Multivariate modeling and other techniques can be used to adjust for these effects so long as they are present in the data.

If these limitations are addressed in the study design, data analysis and interpretation; then any study findings using administrative data can still provide valuable additional information to the available evidence.

## 1.3. International data linkage systems

Prior to the turn of the century there were only a handful of data linkage systems worldwide. However, data linkage involving medical records has been available for decades. These well established systems that were key to the development of data linkage will now be discussed.

### 1.3.1. The Oxford record linkage study (ORLS)

The ORLS was established by Acheson in 1962 as the worlds first data linkage system.<sup>51</sup> He had alluded to the benefits of developing such a system in the BMJ in 1961 when he stated that the analysis of medical records linked nationally would

*‘... provide excellent morbidity statistics and create a science of prognosis...These would be a base from which field studies of the epidemiology of the important diseases of the day would spring...’<sup>52</sup>*

The ORLS was initially a jointly funded project between the NHS’s Oxford Regional Health Authority and the Oxford University Unit of Clinical Epidemiology and produced ad hoc analyses for health care providers and specific multi-centre audit reports annually.<sup>53</sup> It comprises over 10 million records from a historical population of over five million people in the Oxford region; consisting of computerised, irreversibly anonymised abstracts of records of morbidity, births and deaths since 1963 linked using nationally approved identifiers of subject and institution.<sup>54</sup> In 1999, responsibility for the ORLS was transitioned to The Oxford University Unit of Health-Care Epidemiology. At the same time a directive was delivered from The English national Department of Health to cease collecting data pertaining to patients’ names and addresses. With the mainstay of it’s linkage methodology removed (patients’ names and addresses) the collection of data for the ORLS ceased and subsequently all patient identifiers were stripped from the data sets.<sup>53</sup> The ORLS remained at a standstill until the UK regulatory framework caught up and the unit was commissioned to link hospital and mortality data across the whole of England in 2003.<sup>53</sup> This provided the data that allowed the ORLS to be maintained to the present date.

The ORLS has been used to study long-term trends in hospital admissions by individual specialty and clinical condition, studies of postoperative mortality and other adverse outcomes of care, studies of suicide risk after discharge from psychiatric care, studies of associations between clinical conditions and studies of the use of hospital care by the elderly and the 'compression of morbidity' hypothesis.<sup>53</sup>

### **1.3.2. Information and statistics division Scotland (ISD Scotland)**

Scotland was the first country internationally to be able to perform a wide range of population health studies using linked data at a national level. In 1974, an Information and Statistics Division was created to collect, store and disseminate statistical information about all patients treated within the National Health Service in Scotland. The linked data sets included morbidity, maternity, neonatal and mental health records, cancer notifications and records of ambulance and emergency centre attendances. In 1992, a Scottish Central Population Index issued a single, unique NHS identification number to each individual in the entire population of Scotland and this has been also available for matching.

At present, data linkage in Scotland uses routine automated probabilistic matching of personal identifiers, with minimal clerical review. Research supported by the system has studied patient stays and episodes, incidence and prevalence of diseases, multiple admissions, pathways of care, case-control and cohort studies; the system has also been used for national audits and to generate outcome indicators.<sup>55</sup>

### **1.3.3. The Manitoba Population Health Information System**

The Canadian University of Manitoba Centre for Health Policy houses the Manitoba Population Health Information System and is jointly funded through government and competitive research grants.<sup>56</sup> The provincial health department of Manitoba has supplied anonymised electronic health care utilisation files to a repository at the Centre since the 1970s. These files are linkable using a scrambled identifier called the Manitoba Health Services Commission number, which is unique to a family rather than an individual

(creating issues when children leave home).<sup>56</sup> Manitoba Health does not have a data linkage unit, but employs consultants on an ad hoc basis for this purpose. The repository contains over one billion records from the Manitoba Health Services Insurance Plan Registry, as well as health insurance claims from physicians and health care facilities, hospital files, medical claims from patients and long-term care data.<sup>56</sup> The Manitoba Office of Vital Statistics and Cancer Care also provide data to the repository.<sup>56</sup>

Whilst not a government agency, the centre has a contract with the provincial health authority to complete five major studies of health care annually.<sup>56</sup> Project topics are selected from a larger list and jointly negotiated by the Deputy Minister for Health and the Director of Centre.<sup>56</sup> Studies in Manitoba have focused on the quality of care, service provision by regional health authorities, physician workforce, financial and cost issues.<sup>57</sup>

#### **1.3.4. Population Data British Columbia**

The British Columbia Linked Health Database (BCLHD) was established by the Centre for Health Services and Policy Research at the University of British Columbia in 1996. It oversaw over 120 projects using the Database. In 2009, the BCLHD and its data holdings transitioned to Population Data BC. Population Data BC was established as an inter-jurisdictional system to aid in research on the 'determinants of human health, well-being and development'. Linkage of data across sectors, such as health, education, early childhood development, workplace and the environment are possible through the service.<sup>58</sup> The system covers the data sets of the medical services plan, PharmaCare, hospital separations, continuing care, birth registrations, death registrations, mental health episode care records, early childhood data, Worker's Compensation Board and the British Columbia Cancer Agency cancer incidence file, and spatial data.<sup>58</sup>

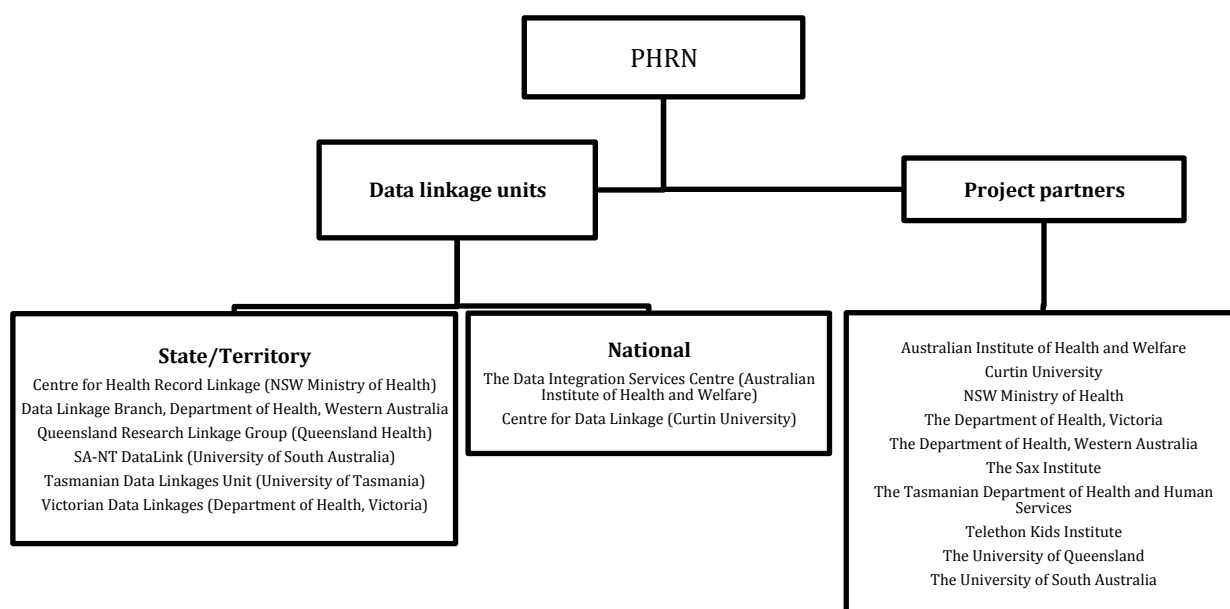
### **1.4. Data linkage in Australia**

The Population Health Research Network (PHRN) was established as a national network in 2009 to provide data linkage infrastructure across Australia as part of the National Collaborative Research Infrastructure Strategy. It is funded

jointly by the Australian Commonwealth Government, State and Territory governments, universities, and research institutes. The PHRN is project lead by The University of Western Australia and comprises a network of data linkage units that services each State and Territory in Australia and two national data linkage units for cross-jurisdictional linkages (Figure 1-2).<sup>59</sup>

A unique feature of the PHRN is the development of the Secure Unified Research Exchange (SURE) by the Sax Institute. This purpose built remote-access data research laboratory allows researchers to work on approved data extracts through a virtual computer while the data remains stored in a highly secured environment. The benefits are that it minimizes the risk of privacy and confidentiality breaches since data are not stored on local computers/networks, improves the accessibility of data to researchers, and facilitates collaboration between researchers across institutes.<sup>60</sup>

The facilities and infrastructure developed by the PHRN make it unique worldwide since very few countries (notably the UK, Canada and some Scandinavian countries such as Sweden and Demark) have the capability to perform population-based data linkage.



**Figure 1-2 - Overview of the Population Health Research Network (PHRN)**

## **1.5. The WA Data Linkage System (WADLS)**

### **1.5.1. Western Australian population**

Western Australia covers a land area of 2.5 million square kilometres with a population of 2.4 million people.<sup>61</sup> Its capital city, Perth, is one of the most isolated in the world. The vast majority of the population (>70%) is located in the state's southwestern corner and the remainder scattered sparsely across the state. The population is bordered by the Indian Ocean to the west and a vast expanse of desert to the east.<sup>62</sup> This relative geographical isolation minimises the degree to which patients travel out-of-state to use health care services and creates a 'captive' population that is ideal for population-based research.

### **1.5.2. The WADLS technology**

The WADLS is administered by the Data Linkage Branch within the WA Department of Health.<sup>63</sup> It uses best practice computerised probabilistic matching to create a dynamic master linkage key between more than 40 population-based administrative and research health data collections in WA). The linkages mean that the total historical population (3.7 million over more than 30 years) can be researched for all major diseases, disease risk factors and health service utilisation and outcomes. The system is built on a foundation of nine core elements: birth, death and marriage registrations, hospital separations, midwives' and cancer notifications, mental health service encounters, emergency presentations and electoral roll registrations. A key aspect of the systems design is the separation of linkage-related processes from those operating on sensitive clinical and service data. Thus, the WADLS is not a database repository but instead consists of pointers or indices to source data elements known as the Master Linkage Key.<sup>64</sup> The data to which it points is still maintained under the jurisdiction of individual data custodians and only upon a formal data request is the data retrieved from the relevant custodian.

The WADLS is both retrospective and prospective, being updated routinely with the additional capability for creating links within and between new external and internal data resources. Linkages are identified using probabilistic matching techniques,<sup>65</sup> based on unit medical record number (unique only to public hospitals), full name and address, phonetic compression algorithms and

demographic information such as date of birth, gender and postcode. Linkage to health related events for individual subjects are ordered chronologically to form a 'chain of links'. These links are readily broken and re-joined to insert new links or to delete incorrect ones allowing huge flexibility for expansion. Clerical checking is undertaken for possible matches in a 'grey zone' between definite matches and non-matches.

The accuracy of linkages has been well validated with the average proportion of invalid links (false positives) and missed links (false negatives) estimated as 0.11%.<sup>66</sup> An audit in 2001 and 2002, involving sampling and detailed clerical scrutiny of linked chains that may contain up to 2000 links, resulted in an estimate of < 0.3% of chains containing one or more incorrect links.<sup>67</sup>

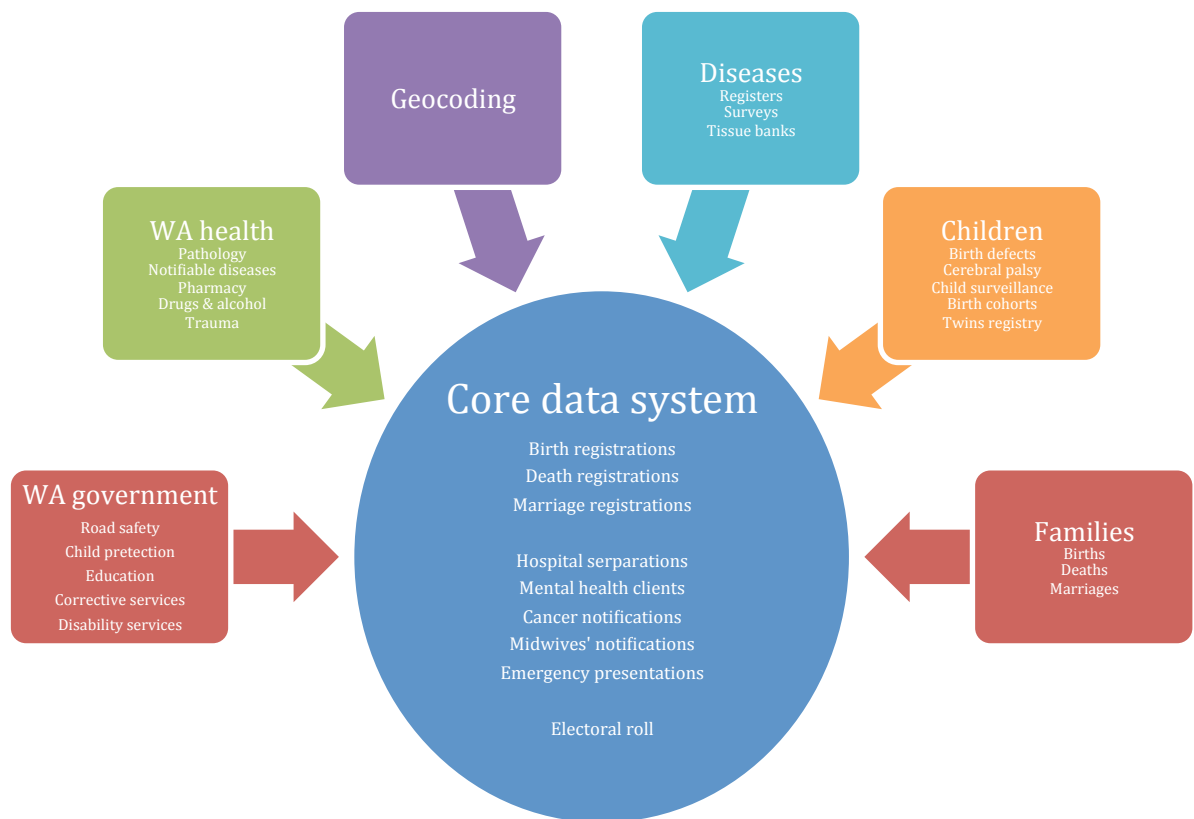
### ***Geocoding***

A unique feature of the WADLS is the ability to assign latitude, longitude and census areas to data using locally developed address parsing software and spatially referenced data sets provided from the WA Land Information System. These geocoded references can be used to associate health events with environmental attributes and to provide unprecedented accuracy in the assignment of social disadvantage and remoteness indices.<sup>68</sup> This enables the geographic distribution of patients to be defined at a given point in time and, combined with linked health data, it supports a cross-sectional view of socio-demographic determinants of health service utilisation and outcomes, and a longitudinal view of residential history in patients with chronic conditions.

### ***Genealogical linkage (Family Connections)***

The Family Connections Register aims to contain family links between children and legally registered parents.<sup>69</sup> The aim is to identify family links of all nuclear families (mothers, fathers and children) that include at least one child who a) was born in WA from 1950 onwards and b) is or was registered on the State Electoral Roll and resident in WA for at least one year from 1980 onwards. Family links, used in combination with linked health records, allows population-based genetic and human genome research with emphasis on characterisation of gene-gene and gene-environment interactions.





**Figure 1-3 The Western Australian data linkage system**

### **1.5.3. Data access and privacy**

In response to rising concerns for patient privacy there has been an increase in the legislative and regulatory requirements for access to linked health data for medical and health research. This has resulted in a broader system of protocols being developed progressively within the WADLS to address the concerns of consumers and data custodians with respect to privacy and data release.<sup>64</sup>

Access to the WADLS is granted only to researchers who have the appropriate Human Research Ethics Committee approvals to conduct their research and who have been given permission by the relevant data custodians. This ensures the data requested is appropriate for the proposed research. Strict protocols

designed to protect confidentiality and security of the data must then be followed, and researchers are strongly encouraged to use unidentifiable data.<sup>63</sup>

Rather than increasing the risk to privacy in the community it has been shown that the WADLS has significantly reduced the exposure of private and confidential person health information in WA. This is because access to personal details in linked data is confined to a small linkage group that adhere to rigorous, strict privacy and confidentiality requirements. As linked data sources have come online the requirement for named data in studies has declined dramatically from 90% in 1990 to 36% in 2003.<sup>41</sup>

Information systems have been developed using data linkage methodologies in numerous sites across the globe to provide infrastructure that supports research.<sup>57,70</sup> Systems that are historically well known internationally for their record linkage research include but are not limited to: the Oxford Record Linkage Study, the Scottish Record Linkage System, Rochester Epidemiology Project, Manitoba Population Health Information System, the British Columbia Linked Health Database, and the WADLS.<sup>57,66</sup>

## **1.6. Use of large administrative databases in ophthalmic research**

Large administrative databases and their linkage have been used in ophthalmic research for decades across a broad range of studies including studies of disease surveillance, disease aetiology, health service utilisation and health outcomes (including post-marketing surveillance):

### **1.6.1. Disease surveillance**

Data on prevalent or incident events is required to understand patterns of disease in the community and may be readily available in health administrative databases (with the caveats already outlined). Large datasets are particularly useful in the study of rare diseases due to the sheer size of the population they cover; and since many span decades, they are also ideal for studying the longitudinal patterns of disease. For example, the incidence of primary angle closure glaucoma (PACG) was first described by Erie et al in 1997 using hospital administrative data from the Rochester Epidemiology Project (REP); they reported an annual incidence of 8.3 per 100,000 (95% CI, 5.6-11.0) in the over 40 year olds in Olmstead County, Minnesota for 1980-1992.<sup>71</sup> A similar study using hospital admission data in Singapore by Wong et al in 2000 found the annual incidence of PACG in an Asian population was higher at 11.1 per 100,000 (95% CI, 10.4-11.8).<sup>72</sup> Hu et al used whole-population health insurance claims data from 503,687 people in Taiwan to describe the relationship between cataract surgery and admission for acute angle closure over the eight-year period 1997-2004. They found a significant correlation between the decline in acute angle closure and the rise in cataract surgery (Spearman rank  $r = -0.407$ ,  $P < 0.001$ ).<sup>73</sup> Numerous other studies have examined the incidence and/or prevalence of a range of eye conditions including glaucoma,<sup>74-78</sup> diabetic retinopathy,<sup>78,79</sup> age-related macular degeneration (ARMD),<sup>79,80</sup> co-morbidity with ARMD,<sup>81,82</sup> retinal detachment,<sup>83-85</sup> sixth nerve palsy,<sup>86</sup> strabismus,<sup>87</sup> dry-eye disease,<sup>88</sup> retinopathy of prematurity,<sup>89</sup> ocular trauma,<sup>90-92</sup> retinal vein occlusion,<sup>93</sup> endophthalmitis,<sup>92,94-98</sup> and spinal surgery related posterior ischemic optic neuropathy.<sup>99</sup>

It should be noted that most stand-alone datasets capture only a subset of the population and are limited in their ability to derive true population incidence and prevalence measures. Data linkage can improve this by facilitating analysis across multiple data sources in a single population to allow greater accuracy in the identification of incident events. For example, linking cancer registry data with data from a local cancer referral centre in Germany increased the incidence of uveal melanoma by nearly four times compared to using cancer registry data alone (from 2.3 to 8.6 cases per million PY).<sup>100</sup>

### **1.6.2. Disease aetiology**

Although it is not possible to establish causality in retrospective observational studies, administrative database studies can assist in identifying potential factors in the aetiology of ocular disease to direct further study in a time and cost efficient manner. This is particularly useful in the study of rare diseases when large numbers are required in order to establish any meaningful associations. Vajdic et al used data from the Australian nationwide kidney dialysis and transplant registry, linked with the cancer registry, to generate a cohort large enough to study the association between immunosuppression and the rare disease ocular squamous cell carcinoma (SCC). The study included 10,180 renal transplant patients over 86,898 person-years follow-up and found a 20-fold increase in the incidence rate of ocular SCC in immunosuppressed patients (IRR 19.5, 95% CI 6.3-45.5).<sup>101</sup> They were the first to report on the association outside of the known link with human immunodeficiency virus and added further weight to the hypothesis that immunodeficiency has a role in ocular SCC. In another more recent study, Bonamy et al reported findings from their population-based study using linked population registries examining the risk of late retinal detachment in preterm infants born in Sweden.<sup>102</sup> This large study of over 3 million births spanned 35 years since 1973 with a median follow-up of 17.4 years. Retinal detachments after preterm birth are rare with just 0.029 cases per 1000 person-years. Significant risk factors were birth before 32 weeks and male gender. The risk (HR) of retinal detachment for extremely preterm infants (<28 weeks) and preterm infants (28-31 weeks) was 19.2 (95% CI 10.3-35.8) and 4.32 (95% CI 2.70-6.90) respectively for infants

born 1973-1986; which decreased to 8.95 (95% CI 3.98-20.1) and 2.80 (95% CI 1.38-5.69) respectively for infants born 1987-2008 after the introduction of routine retinopathy of prematurity screening. Males were over twice as likely to have a late retinal detachment (HR 2.56, 95% CI 2.08-2.78).

Other examples include a study on the association between reduced sunshine exposure and increased angle closure glaucoma;<sup>103</sup> genetics and open angle glaucoma;<sup>104</sup> diabetes and an increased risk of glaucoma,<sup>105</sup> sixth nerve palsy<sup>86,106</sup> and acute conjunctivitis;<sup>107</sup> risk factors for central retinal vein occlusion;<sup>108</sup> and the lack of association between vitamin D deficiency and macular degeneration.<sup>109</sup>

### **1.6.3. Health service utilisation**

Understanding patterns and trends in eye service use is essential to adequate planning by governments and agencies to anticipate service needs and costs. This is particularly important in understanding variations in the patterns of care between clinical sub-populations (e.g. sociodemographic and geographic groups) to identify areas of service deficiency or inefficiency.

Large health administrative databases are ideal for studies of health service utilisation since they are derived from the delivery of these services. This means every clinical service encounter is 'captured' to provide an entire-population cohort on which to conduct research without the need to extrapolate findings. The richness of information on service provision contained in these databases is reflected in the volume of ophthalmic research published in this area. The majority of studies have examined trends and patterns of ophthalmic services use over time, and across socio-demographic and geographic groups. Particular attention was paid to trends in eye surgery and use of ophthalmic drugs (particularly for glaucoma).

#### ***Patterns of care***

Establishing trends in ophthalmic service use over time is easily achieved using administrative databases since most span decades. The first data linkage study to examine trends in ophthalmic services was by the ORLS, in the Oxford region of the UK in 1991.<sup>110</sup> The study found the use of ophthalmic services increased 16.3% over an 11-year period (1975-1985), while the length of stay per

admission to hospital decreased. Subsequently Ellwein et al analyzed data from the US Medicare database of over 65 year olds to look at trends in eye care utilisation and the type of providers providing this service.<sup>111,112</sup> They found a 6.7% rise (41.4% to 48.1%) in the proportion of people accessing eye services between 1991 and 1998; and that ophthalmologists provided the majority of eye care billed under Medicare (71%).

Identifying areas of service deficiency or over-servicing is important in the equitable distribution of limited health resources particularly to vulnerable populations. Such patterns of service delivery are readily identified using health administrative databases that cover large population cohorts across geographic and demographic boundaries. This allows patterns of service delivery across socioeconomic, race, gender, and geographic groups to be examined. In WA we used linked whole-population hospital administrative data to describe the growing inequity in the cataract surgery rate for rural/remote (metropolitan patients had 24% more surgery) and lower socioeconomic groups (the disadvantaged had 9% less surgery), despite an overall improvement in access to cataract surgery.<sup>113-115</sup> Other studies have examined similar socioeconomic and geographic variations in cataract surgery utilisation in the UK using the ORLS<sup>116</sup> and the US using Medicare data.<sup>117-119</sup>

Racial variation in the treatment of glaucoma was reported in several US studies using Medicare/Medicaid data. Most found the rates of eye service use in blacks were as much as 50% lower than whites despite an increased prevalence of glaucoma in the black population.<sup>120-124</sup>

Other examples of studies of patterns of eye service utilisation in specific populations include those in women,<sup>125</sup> children,<sup>126</sup> and diabetics.<sup>127,128</sup>

### ***Trends in surgery***

Surgical trends are particularly suited to study using large administrative databases since such encounters are almost universally recorded. Cataract surgery rates have increased dramatically in studies from most Western countries since the adoption of phacoemulsification, with most reporting a doubling in rates every 10 years<sup>119,129-134</sup> that are projected to increase further.<sup>135</sup> Conversely the introduction of prostaglandin analogues and

increased uptake of laser trabeculoplasty<sup>136</sup> has seen the rate of glaucoma filtering surgery decline significantly by between 29 and 75% over a 10-year period since the mid-1990s.<sup>137-141</sup> Retinal procedures have also changed significantly in the US medicare population between 1997 and 2007, particularly an explosion in intravitreal injections (<5000 procedures in 1997 to 812,413 procedures in 2007); 72% increase in vitrectomy and 69% decrease in scleral buckle only surgery; and an 86% increase in pan retinal photocoagulation procedures.<sup>142</sup>

### ***Pharmacoepidemiology***

Patient compliance with prescribed treatment in chronic diseases such as glaucoma is notoriously poor.<sup>143</sup> Pharmaceutical claims and health insurance databases have been used extensively in the US to study general trends and patterns in eye drop utilisation and the factors affecting their use.<sup>144-148</sup> Claims data has the advantage over other research methods since they avoid recall bias, which can be problematic in studies that rely on self-reporting.

Patient adherence and persistence with their glaucoma medication provides an insight into compliance and also the effectiveness and tolerability associated with a particular drug or class of drug. Reardon et al used health and pharmaceutical claims data from the Protocare Sciences managed care database to study over 28,000 patients aged over 20 years who were dispensed topical ocular hypotensives.<sup>149-152</sup> They found that discontinuation rates were high; only 33% of those prescribed latanoprost were still using it after 12 months and continued use in other drug classes were even lower (19%). They also found latanoprost had less rates of discontinuation compared to all other glaucoma medications, including the other prostaglandin analogues. Similar findings were reported in later studies. Nordstrom et al found half of patients had discontinued treatment by 6 months and that those taking prostaglandins were 60% less likely to discontinue compared to beta-blockers and carbonic anhydrase inhibitors.<sup>153</sup> Other studies using claims data further support the findings from these studies,<sup>154-161</sup> including one from Australia using national population-based pharmaceutical claims for 357,099 patients that confirmed superior persistency for prostaglandins.<sup>162</sup>

Pharmacoepidemiology studies using administrative data have their own unique limitations.<sup>25</sup> Caveats that should be considered when estimating patient compliance include: inaccuracies when a patient is given sample medications or their medication is obtained from outside their insurance plan; being unable to ascertain whether cessation of a prescription is due to a management decision by the patient's physician or a non-compliant patient; and that simply dispensing a prescription does not mean the patient is actually using the medication as prescribed. We also know from validation studies using chart review that for glaucoma, claims data alone tends to overestimate disease severity and is not able to correctly identify which patients are truly new to treatment.<sup>25,48,49</sup> The Glaucoma Adherence and Persistency Study attempted to address some of these limitations by using a combination of health insurance claims data and pharmacy claims data, validated with chart review and structured interview of patients and physicians.<sup>49</sup> Even taking these factors into account, adherence and persistency rates were still poor. They found that only 10% of patients were continuously persistent with prescribed treatment over a 1 year period and at 1 year only 59% were adherent to any ocular hypotensive treatment.

#### **1.6.4. Health outcomes**

In contrast to traditional clinical trials, health outcomes research examines clinical practice as it is actually performed in the community to answer questions about 'real world' effectiveness. Health administration databases, being born out of actual practice, are therefore particularly well placed for outcomes research. They also do not suffer from some of the limitations inherent in other traditional cohort, case-control and randomized controlled trials. Studies of health outcomes in ophthalmic research have generally focused on surgical safety, monitoring adherence to best practice, and post-marketing surveillance.

##### ***Surgical safety***

Outside of the clinical trials, monitoring surgical safety typically relies on reporting adverse events through case series from single or multiple centers or clinics. Events identified in this way may be selective or incomplete. They do not



necessarily reflect the practice occurring in the wider community where there is likely significant variation in surgical case mix and complexity, surgeon experience and quality of available equipment. While clinical registries may address most of these issues, administrative datasets are more likely to be complete and less easily 'gamed'.

The excellent safety profile of cataract surgery requires very large sample sizes over prolonged periods of time to identify and adequately study trends and risks of adverse events. Using Medicare data, Stein et al found just 0.5% of 220,000 cataract surgeries resulted in a serious adverse event over a 13-year period (1994-2006); and because of the large sample size they were able to report on a significant declining trend.<sup>163</sup> Bell et al found surgeon operative volume was important in the risk of adverse outcomes by pooling data from provincial health insurance claims data for over 230 surgeons and 284,797 cataract surgeries in Ontario; surgeons performing over 1000 cataract procedures per year had 0.1% adverse events compared to 0.8% in those performing 50-250 procedures (OR 0.14, 95%CI 0.09-0.23).<sup>164</sup>

A large sample size is particularly relevant to the study of rarer events e.g. endophthalmitis. Studies using health insurance claims and hospital administrative data showed the incidence of endophthalmitis ranged between 1 and 2 per 1,000 surgeries.<sup>96,98,165-170</sup> Sample sizes in excess of 100,000 in these studies allowed identification of potential risk factors including increased risk in males, the elderly, complicated surgery, lower surgeon volume, and surgery in private facilities.<sup>96,98,165-170</sup>

Javitt et al used US medicare claims data to be the first to demonstrate a statistically significant increased risk of retinal detachment after intracapsular, extracapsular and phacoemulsification cataract surgery.<sup>167,171</sup> They found greatest risk of retinal detachment with intracapsular surgery (1.55%) and were the first to describe an increased risk with phacoemulsification compared to extracapsular surgery (1.17% vs 0.9%). They also found statistically significant increased risk in males (RR 1.66), younger patients (RR 3.70 65-69 vs 80-89 yrs), whites (RR 3.85) and surgery where anterior vitrectomy was performed (RR 4.5). It was only through a large sample size that they were able

to confirm these findings (which had previously been suspected but not confirmed due to limited sample sizes of previous studies). Other large database studies have since confirmed these findings.<sup>84,172-176</sup>

The combination of relatively uncommon procedures and rare complications further highlights the need for whole-population methodology and large sample sizes. Haargaard et al demonstrated this in their report of the long-term risk of retinal detachment after paediatric cataract surgery in Denmark 1977 – 2005.<sup>177</sup> Despite 28 years of data and 1043 eyes (656 children) having paediatric cataract surgery, only 25 eyes (23 children) developed a retinal detachment. They demonstrated that 3% of children with isolated paediatric cataract will develop a retinal detachment within 20yrs of surgery. Significant risk factors were mental retardation (23%) and cataract plus other ocular or systemic pathology (16%). Importantly primary posterior capsulotomy and anterior vitrectomy did not increase the risk of retinal detachment.

One caveat of purely database studies is their limited ability to study a broad range of risk factors as they may not be coded, or the accuracy of coding for that risk is inconsistent e.g. smoking. Case-control methodologies using chart review for the cases and a random sample of the un-affected population may overcome this problem. For example the Endophthalmitis Population Study of Western Australia used population-wide hospital administrative data for an entire cataract surgery cohort of 117,083 over a 20-year period and 205 cases of endophthalmitis. Every case of endophthalmitis was validated with chart review and a nested case-control study was used to identify important surgical and non-surgical risk factors, including previously unreported associations with winter procedures (OR 1.48 95% CI 1.00–2.18) and concurrent eyelid surgery (OR 23.50, 95% CI 8.50–64.98).<sup>169,170</sup>

A similar nested case-control study examined risk factors for retinal detachment after cataract surgery in the Medicare population was conducted by Tielsch et al<sup>178</sup> after their previous claims data study suggested a four-fold increased risk after Nd:YAG capsulotomy.<sup>179</sup> They confirmed this risk (OR 3.8, 95% CI 2.4-5.9) along with other risk factors for retinal detachment that

included: axial length, a history of lattice degeneration or retinal detachment or ocular trauma, and refractive error.<sup>178</sup>

The other cataract surgery outcomes studied using linked data include the impact of cataract surgery on the increased risk of corneal oedema;<sup>180</sup> reduced vehicle crash risk through linkage with road accident databases;<sup>181,182</sup> surprisingly increased risk of falls, through linkage with emergency room databases;<sup>183,184</sup> reduced admission for depression, through linkage to mental health services;<sup>185</sup> and reduced risk of death, by linking to death registers.<sup>186,187</sup>

Studies reporting outcomes for other surgical procedures are fewer in number and include adverse events after glaucoma-related procedures<sup>188-190</sup>, pars plana vitrectomy,<sup>191</sup> and penetrating keratoplasty.<sup>192</sup>

#### ***Monitoring adherence to best practice***

Administrative datasets are being increasingly used to audit adherence by patients and their physicians to 'best practice'. They are felt to offer a more accurate picture of real world practice since they are not affected by recall bias present in traditional surveys or clinical registries. Screening for diabetic retinopathy is particularly suited to such an approach due to well-established clinical guidelines and the ability to readily identify service encounters within most administrative datasets. Reports from health claims databases suggest eye examination rates for diabetics are universally poor. Wang et al found only 53% of 175,015 diabetic Medicare beneficiaries had at least 1 eye care visit in a 1 year period, and only 67% within 2 years.<sup>193</sup> Similar proportions were reported using claims data elsewhere in the US.<sup>74,127,194-197</sup> While in Nova Scotia, Canada longitudinal claims data over 10 years showed only 14.4% of diabetics had at least one eye examination consistently each year.<sup>198</sup> Factors consistently associated with less attendance were younger age, male gender, ethnic minorities, lower education level, and lower socioeconomic status.<sup>193,197,199</sup> Direct mail reminders to improve low attendance was studied but they were found to have only a short lived, modest effect at best..<sup>200,201</sup>

The practice patterns of physicians treating glaucoma has received some attention. Friedman et al found using health insurance data that 17% of glaucoma suspects and 16% diagnosed with glaucoma did not have a

documented follow-up. They also found only half of these patients had at least one VF test within the follow-up period and just 13% had optic disc imaging (median follow-up 440 days).<sup>202</sup> Coleman et al found less than half of US medicare patients undergoing glaucoma surgery had gonioscopy performed in the preceding 4-5 years,<sup>203</sup> and just 70% had a field test in the preceding 1 year.<sup>204</sup> More recently Stein et al demonstrated a change in practice for glaucoma monitoring with use of visual field testing falling by 44% while the use of other ocular imaging modalities increased by 147% from 2001 to 2009.<sup>205</sup>

### ***Post-marketing surveillance***

Monitoring the safety of new drugs or medical devices following their widespread release into the community is an important part of health outcomes research. Approvals for their use are based on stringent testing in the setting of highly controlled clinical trials; but these trials are generally limited by small samples sizes of select populations that perhaps bear little resemblance to the wider clinical setting where the products are used. So post-marketing surveillance becomes essential to assess the safety of new medical products once released.

Information regarding medication safety is typically managed through national drug surveillance bodies e.g. the US Food and Drug Administration (FDA) agency. Reporting adverse events to these bodies commonly relies on voluntary submission, which may be from multiple sources i.e. directly from the manufacturing company, the public, or independent organizations. The problem with this approach is it cannot provide useful population incidence rates since the population at risk is not quantified. There is also significant under-reporting and variability in the quality of reporting.<sup>206</sup>

Administrative databases are ideal to assist in post-marketing surveillance due to their large population cohorts allowing rare adverse events to be studied, ready access to current data, and relative cost effectiveness compared to traditional trials. The US FDA has recognized their value in several reports, and they recommended a greater use of population-based datasets to enhance post-marketing surveillance systems.<sup>207</sup>

There are a limited number of studies making use of administrative and linked datasets in post-marketing surveillance of ophthalmic drugs and devices despite them being ideal for this. French et al have published several studies using clinical and pharmacy data from the US Veterans Health Administration database that explored the association between drugs and eye disease. They found a temporal relationship between commencement of amantadine and the onset of corneal edema in a small proportion of patients (0.12%), which supported earlier case reports of the association.<sup>208</sup> They reported that 479,489 men using phosphodiesterase inhibitors had a small, but not significant, increased risk of anterior ischemic optic neuropathy;<sup>209,210</sup> and no association with central serous retinopathy.<sup>211</sup> They also found no association between the bisphosphonates and uveitis/scleritis (OR 1.23, 95% CI 0.85-1.79).<sup>212</sup> In another study they demonstrated an interesting reduced risk of death with any glaucoma medication (OR 0.93; 95% CI 0.90-0.95),<sup>213</sup> which confirmed findings from earlier large database studies.<sup>214,215</sup>

The safety of the anti-VEGF treatments for neovascular ARMD was recently studied. French et al found no difference in the risk of mortality for bevacizumab or ranibizumab (OR 0.89, 95%CI 0.74-1.06) in a cohort of 3,210 patients given intravitreal anti-VEGF and 117,364 unexposed ARMD patients.<sup>216</sup> This was supported by a Canadian study that used insurance claims data for 91,378 patients in Ontario.<sup>217</sup>

Other examples include finding no risk of congestive heart failure with topical glaucoma medications;<sup>218</sup> inconsistent results about the reduction in Nd:YAG laser capsulotomy rates with the introduction of square edge intra-ocular lenses,<sup>219</sup> an increased risk of retinal detachment with oral fluoroquinolones,<sup>220</sup> and the apparent protective effect of statins in open angle glaucoma.<sup>221</sup>

### **1.6.5. Health economics**

Determining the cost and demand for ophthalmic services is important for health care planning, particularly in the climate of dwindling health budgets and rapidly increasing health care costs. Administrative data are particularly useful for estimating these costs since they are recorded at the point of service and usually contain billing information to calculate actual costs.

Examples are numerous, particularly studies using Medicare claims data. Findings have included: cataract surgery cost USD\$2500 in 1991;<sup>222</sup> there was a 10-25% decrease in the cost of eye care to Medicare during the 1990s despite an increase in the proportion of beneficiaries receiving eye care (due to a reduction of cataract surgery payments);<sup>111,223</sup> physician reimbursement as fee for service is associated with approximately twice the rate and cost of cataract surgery compared to a cost capitation model;<sup>224</sup> fee cuts for ophthalmic surgery increased volume but had no effect on overall cost;<sup>225</sup> increasing surgeon supply increased access to surgeons but did not increase the demand for services by individual patients;<sup>226</sup> vision loss is associated with an extra USD\$2,193 to \$4,443 in health care costs or USD\$2.14 billion for the entire Medicare population in 2003;<sup>227</sup> introducing prostaglandins for glaucoma increased adherence without significantly increasing costs;<sup>155</sup> and there is an increased cost associated with post-operative complications like endophthalmitis (US\$16,142 higher claims per case)<sup>228</sup> and cystoid macular edema (40-50% higher claims and payments).<sup>229</sup> Studies have also examined the cost of providing specific ophthalmic medications (e.g. eye drops),<sup>230,231</sup> while others have quantified the health expenditure associated with diabetic retinopathy<sup>232,233</sup> and diabetic macular oedema;<sup>234</sup> ARMD;<sup>235,236</sup> and primary open angle glaucoma (USD \$242 to \$1,570).<sup>137,237,238</sup>

## **1.7. Conclusion**

Large administrative and linked databases are readily available and rich sources of information for ophthalmic research. Much use has already been made of them with a trend towards increasing output as researchers realise their value in addressing a wide range of research questions, particularly relating to ophthalmic service utilisation and outcomes. The WALDS is a well established, validated and internationally regarded rich resource that is ideal for population-based research in ophthalmology. While administrative datasets are not without their limitations, many of these can be overcome with the appropriate study design, analysis and careful interpretation. Their benefits in providing a 'real world' view of ophthalmic disease, services and outcomes in a timely fashion that conserves the health dollar should not be underestimated.

## Chapter 2

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# Is Western Australia representative of Australia?

## Research output

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### Published manuscripts

1. **Clark A, Preen DB, Ng JQ, Semmens JB, Holman CDJ. Is Western Australia representative of other Australian States and Territories in terms of key socio-demographic and health economic indicators?** *Australian Health Review* 2010; 34 (2): 210-215.

## 2.1. Background

The WA population is isolated and vast - only 10% of the total Australian population reside in the state and most (>70%) are concentrated in its' capital city, Perth. The rest of the population are scattered over an area over ten times the size of the United Kingdom. This population is separated from the rest of the Australian population by an expanse of desert to east and the Indian ocean to the west (Figure 2-1).<sup>61</sup> While one may surmise this could create a 'captive' population ideal for longitudinal, whole-population research; anecdotally there is concern that this isolation may lead to systematic socio-demographic and socioeconomic differences. Thus limiting the generalizability of any research findings produced from population-based research in WA.

With this in mind, the following paper explores how the WA population compares to other Australian states and territories in key socio-demographic and economic indicators. Demonstrating that the WA population is similar to other Australian jurisdictions adds weight to the argument that findings arising from population-based research in WA are externally valid to the rest of Australia.



**Figure 2-1** - Western Australia. (Google Earth)



**Clark A, Preen DB, Ng JQ, Holman CDJ. Is Western Australia representative of other Australian States and Territories in terms of key socio-demographic and health economic indicators? Australian Health Review 2010;34(2):210-5.**

## Is Western Australia representative of other Australian States and Territories in terms of key socio-demographic and health economic indicators?

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### Abstract

**Objective.** To evaluate the extent to which Western Australian (WA) represents the broader Australian population in terms of key socio-demographic and health economic indicators.

**Methods.** We compared key demographic, social and health economic indicators across all Australian States and Territories from Australian government publications in the census years 1991–2006. Jurisdictional averages (JAs) were calculated as the mean ( $\pm$ s.d.) or median ( $\pm$ range). Observed jurisdiction indicators were compared with the JA and ranked according to its representativeness of the JA.

**Results.** WA was among the three closest jurisdictions to the national JA for all socio-demographic and health economic indicators examined, with the exception of uptake of private health insurance (ranked 6th) and per-capita health expenditure (ranked 5th). The Northern Territory and Australian Capital Territory were least representative for the majority of indicators. Excluding the proportions of people living in rural or remote areas (0–100%) and of indigenous origin (0.4–28.8%), variations in the indicators across the jurisdictions were relatively small.

**Conclusions.** Population differences between Australia's States were small, whereas Australia's Territories were least representative of the JA. WA was the most representative population of Australia's eight jurisdictions and continues to be in a strong position to contribute to knowledge of the Australian health system that is applicable Australia-wide.

**What is known about the topic?** The Western Australian Data Linkage system (WADLS) is a highly successful and productive research tool that facilitates population-based health research. A potential criticism and concern of this research surrounds the representativeness of the WA population to other Australian States and Territories. Anecdotally, there is a perception that WA's isolation from other Australian populations may lead to systematic socio-demographic and socioeconomic differences; thus limiting the generalisability of research findings.

**What does this paper add?** This paper compares Australia's State and Territory population profiles and allows researchers to determine the extent to which contextual issues concerning key socio-demographic and health economic indicators may affect the external validity of population-based research arising from any one jurisdiction.

**What are the implications to practitioners?** In the absence of previous evaluations in this area and with the continued emergence of new data linkage systems around the country, this information is important for health researchers and policy makers who may wish to draw conclusions and make policy decisions that rely upon extrapolating findings from population-based studies.

**Additional keywords:** data linkage, demography, population-based research, socioeconomics.

## Introduction

Western Australia's (WA) population is one of the most geographically isolated in the world<sup>1</sup> The majority (>70%) of the States 2.1 million residents are concentrated in its south-western corner and the remainder are scattered widely over an area occupying one-third of the Australian continent.<sup>1</sup> This population has been the subject of over 700 population-based health research projects over the last 10–15 years facilitated by the existence of longitudinal, whole-population, routinely-collected administrative health and medical data collections linked through WA Data Linkage System (WADLS).<sup>2</sup> Research using data provided through the WADLS has varied widely in focus and comprised aetiological, utilisation and outcomes research on whole-population samples.<sup>3–8</sup> Although the general relevance of findings from these studies to the WA population is seldom challenged, the validity of extrapolating the findings to other Australian jurisdictions has anecdotally been questioned. It is argued that the isolation of WA from other Australian States and Territories could lead to systematic socio-demographic and socioeconomic differences from the remainder of the nation, thereby possibly reducing the external validity of research based on the WADLS for the rest of Australia.

Despite such claims, no evaluation has hitherto been reported to support or dispel the suggestion that the geographical isolation of WA leads to non-representativeness of the rest of the country. Consequently, the degree to which research findings on the WA population can be readily applied to the wider Australian context has remained an open question. External validity and the generalisability of research findings to other populations plays a crucial role in their translation into health policy and practice.<sup>9</sup> Our aim was to evaluate the extent to which WA is, or is not, representative of other Australian jurisdictions in terms of key population socio-demographic and health economic indicators.

## Methods

We examined key demographic, social and health economic indicators on the Australian States and Territories in the census years 1991, 1996, 2001 and 2006. Demographic and social indicators examined included median age, sex ratio, percent indigenous population, rural or remote population ratio, out-of-State migration, and proportion of low-income families. Health economic indicators examined included the number of available hospital beds, the proportion of the population disabled, overall health expenditure, Medicare Benefits Schedule (MBS) claims, Pharmaceutical Benefits Scheme (PBS) and Repatriation Pharmaceutical Benefits Scheme (RPBS) payments and the proportion of the population privately insured. These indicators were selected because we felt they are important in health research due to their common use as covariates (e.g. age and sex) or due to their association with health outcomes (e.g. family income). Out-of-State migration was chosen due to its importance in loss-to-follow-up.

Values for each indicator were sourced from publications of the Australian Bureau of Statistics (ABS),<sup>10–22</sup> the Australian Institute of Health and Welfare,<sup>23–26</sup> the Public

Health Information Development Unit,<sup>27</sup> Medicare Australia<sup>28,29</sup> and the Private Health Insurance Administrative Council.<sup>30</sup> Where data were not recorded for a particular census year, data for the year closest to the census year were substituted. Data on low-income families and the prevalence of disability were obtained from special surveys conducted outside of census years.<sup>20–22,27</sup> The definitions for each indicator were those used in their source publications and are shown in Table 1.

An eight State and Territory jurisdiction average of each indicator was calculated as the mean  $\pm$  s.d. or median and range across all Australian States and Territories in each observation year. The jurisdictional average is distinct from the Australian average (calculated by dividing the national total of the indicator by the total Australian population) and recognises that a great deal of administration and decision-making concerning delivery of health services occurs at the State and Territory level. Research findings arising from any one jurisdiction or the nation as a whole should be interpreted in the knowledge of that diversity.

State and Territories were ranked according to their percentage difference from the eight-jurisdiction average for each indicator and closest three identified. An exception to this general method was that for out-of-State migration where we identified the three jurisdictions with the lowest absolute level of outward migration. This was because we took the view that the lowest possible outward migration was far more valuable to improving the internal validity of epidemiological and health services research results than the external validity of proximity to the jurisdictional average.

## Results

### *Socio-demographic profile*

Comparison of socio-demographic indicators is shown in Table 2. Sex ratios were approximately equal across the States and Territories since 1991, except in the Northern Territory (NT) where men outnumbered women by 8–11%. All jurisdictions except the NT were approximately representative of the eight-jurisdictional average with WA among the three most representative States for sex ratio in 1991, 1996 and 2001.

The WA population was the most representative for median age in all census years. The youngest population was in the NT (median age 4.5–5.3 years younger than the jurisdictional average), whereas South Australia (SA) had the oldest population (median age 2.2–2.7 years older than the jurisdictional average).

The proportion of the population who self-identified as indigenous varied considerably across the jurisdictions. In the NT 25–29% of its population were indigenous, whereas WA, Queensland (QLD) and Tasmania had the next highest proportions of indigenous people (range 3.0–3.7%). The Australian Capital Territory (ACT), Victoria (VIC) and New South Wales (NSW) had the lowest (0.4–2.1%).

The NT also had the highest proportion of its population living in rural or remote areas where, based on ARIA criteria (a common method of classifying remoteness in epidemiological research),<sup>31</sup> 100% of the population live in outer regional, remote or very remote areas. Conversely, the ACT had no

**Table 1. Definitions used by data sources for socio-demographic and health economic indicators**  
ARIA, Accessibility and Remoteness Index of Australia

Indicator	Definition
Socio-demographic	
Median age	Age in years. <sup>10</sup>
Sex ratio	Men per 100 women. <sup>10</sup>
Indigenous population	Percentage of State and Territory population who identify themselves as being of Aboriginal or Torres Strait Islander origin. <sup>11–14</sup>
Rural or remote population	
1991	Population clusters of <1000 people or holiday villages of <250 dwellings (i.e. not urban). <sup>15</sup>
1996	Population clusters <200 dwellings (i.e. not an urban centre or locality). <sup>16</sup>
2001 onwards	ARIA score >2.4 (i.e. outer regional, remote and very remote populations). <sup>17,18</sup>
Out-of-state migration	The number of long-term residents <sup>A</sup> who left the State and Territory to go overseas or to another Australian State and Territory <sup>B</sup> with an intended absence of 12 months or more expressed as a percentage of the State and Territory population in that year. <sup>19</sup>
Low income households	
1996	Families with an income <\$21 000 per annum. <sup>27</sup>
2006	Households in the second and third equivalised disposable income <sup>C</sup> deciles. <sup>20</sup>
Health economic	
Available beds	The total number of public acute and psychiatric hospital beds available per 1000 population. <sup>23–25</sup>
Health expenditure	The total recurrent health expenditure from all sources including: State and Territory governments, Australian Government, private health insurance funds, individuals (through out-of-pocket payments) and providers of injury compensation cover. All totals are expressed as per person, based on the mean resident population in each year. <sup>26</sup>
Medicare benefits paid	The total expenditure on Medicare items in each State and Territory per person enrolled with Medicare Australia. <sup>28</sup>
Pharmaceutical benefits paid	The total expenditure on Pharmaceutical Benefits Scheme and Repatriation Pharmaceutical Benefits Scheme items in each State and Territory per person enrolled with Medicare Australia. <sup>29</sup>
Private health insurance	The number of persons with private health insurance as a percentage of the State and Territory population. <sup>30</sup>
Disabled population	Disability was defined as persons with any limitation, restriction or impairment, which has lasted, or is likely to last, for at least six months and which restricts everyday activities. The number of disabled persons was expressed as a proportion of the State and Territory population at the time. <sup>21,22</sup>

<sup>A</sup>Long-term residents refers to those people who have resided in the State and Territory for 12 months or more.

<sup>B</sup>Interstate migration was identified through a change in address registered with Medicare.

<sup>C</sup>Equivalised household income is the household income that is adjusted for the number of adults living in a household, allowing comparison across households of different sizes.

rural or remote residents (0%). The percentage of the WA and SA populations living in rural or remote areas were the most consistently representative of the jurisdictional average across all census years.

Out-of-State migration averaged 2.7–3.2% in most Australian States and Territories. VIC had the lowest out-of-State migration, estimated at ≤2.4% since 1991. SA and WA had the second and third lowest levels respectively in most years, with levels consistently below 3.0%. WA was among the three jurisdictions with the lowest percent out-of-State migration in 1996, 2001 and 2006.

The proportion of households classed as having low-income was 19.1 and 20.4% for the eight-jurisdictional average in 1996 and 2006 respectively. The NT and ACT had the lowest proportion of low-income families recorded, although it should be noted that the NT data mainly pertained to its urban population. NSW and WA were most consistently representative of the jurisdictional average, being within 0.5% of the average in 1996 and 2001.

#### Health economic profile

Comparison of health economic indicators is shown in Table 3. The number of available public acute and psychiatric

hospital beds per 1000 people averaged 2.7–3.0. All jurisdictions except SA and the ACT were among the closest three jurisdictions to the average at least once from 1996–2006. WA was never more than 0.2 beds per 1000 people from the jurisdiction average.

Total health expenditure has averaged \$2191–\$4017 per person across the jurisdictions since 1996–97. Spending was comparable for all except the NT, where spending was \$252–\$937 more per person. NSW and VIC were consistently among the three most representative, whereas the total health expenditure of WA ranked the fourth most representative of the average (\$112–\$184 less per person than the jurisdiction average).

Medicare payments in the NT were \$180–\$308 less per person, and PBS and RPBS payments \$68–\$230 less per person than the jurisdiction with the highest expenditure. The most representative jurisdictions in terms of per capita Medicare payments were WA (\$292.60–\$462.40) and TAS (\$288.50–\$479.40), whereas for PBS and RPBS payments they were WA (\$61–\$252) and QLD (\$75–\$285).

The proportion of the population privately insured was highest in WA (47.4–48%) and lowest in the NT (30.6–34.2%). TAS, QLD and VIC were the most representative of the eight-jurisdiction average (41.5–43.6%).

**Table 2. Comparison of selected socio-demographic indicators for each Australian State and Territory with the eight-jurisdictional average (JA)**  
Values in bold are the three Australian States and Territories closest to the jurisdictional average (except for out-of-State migration where the three lowest values are in bold)

	Year	NSW	VIC	QLD	SA	WA	TAS	NT	ACT	JA (s.d.) <sup>A</sup>
Sex ratio (males per 100 females)	2006	<b>98.2</b>	98.0	<b>99.7</b>	97.5	102.0	97.3	108.0	<b>98.3</b>	99.9 (3.6)
	2001	<b>98.6</b>	97.0	<b>99.1</b>	97.7	<b>100.2</b>	97.1	109.7	97.4	99.6 (4.2)
	1996	<b>98.6</b>	97.6	<b>100.4</b>	97.9	<b>101.1</b>	97.6	111.0	98.5	100.3 (4.5)
	1991	99.1	98.4	<b>100.4</b>	98.5	<b>101.2</b>	98.4	109.8	<b>100.0</b>	100.7 (3.8)
Median age (years)	2006	36.8	<b>36.7</b>	<b>36.0</b>	38.7	<b>36.2</b>	38.8	30.9	34.8	36.1 (2.5)
	2001	35.9	<b>35.8</b>	<b>35.0</b>	37.6	<b>34.9</b>	37.2	29.6	33.3	34.9 (2.5)
	1996	34.4	<b>34.3</b>	<b>33.3</b>	35.6	<b>33.1</b>	34.6	27.8	31.3	33.1 (2.5)
	1991	32.9	32.5	<b>31.8</b>	33.6	<b>31.5</b>	<b>32.4</b>	26.9	29.5	31.4 (2.2)
Indigenous population (%)	2006	<b>2.1</b>	0.6	<b>3.3</b>	1.7	<b>3.0</b>	3.5	27.8	1.2	2.6
	2001	<b>2.0</b>	0.6	<b>3.5</b>	1.7	<b>3.5</b>	3.7	28.8	1.2	2.8
	1996	<b>1.7</b>	0.5	<b>3.0</b>	1.4	<b>3.1</b>	<b>3.1</b>	27.3	1.0	2.4
	1991	<b>1.2</b>	0.4	2.4	<b>1.2</b>	2.7	<b>2.0</b>	25.0	0.6	1.6
Rural or remote population (%) <sup>B</sup>	2006	7.1	5.0	<b>18.1</b>	<b>15.2</b>	<b>15.8</b>	35.2	100.0	0	15.5
	2001	<b>8.0</b>	5.4	21.8	<b>15.8</b>	<b>17.2</b>	36.5	100.0	0	11.9
	1996	9.4	<b>10.6</b>	16.2	<b>11.0</b>	<b>10.7</b>	21.3	18.1	0.6	10.8
	1991	12.3	<b>13.0</b>	20.0	<b>14.8</b>	<b>14.2</b>	27.6	31.6	1.4	14.5
Out-of-state migration (%)	2006	3.1	<b>2.4</b>	2.9	<b>2.4</b>	<b>2.6</b>	3.0	8.6	7.7	2.9
	2001	3.2	<b>2.4</b>	3.2	<b>2.6</b>	<b>2.8</b>	3.5	9.8	7.7	3.2
	1996	<b>2.5</b>	<b>2.3</b>	3.0	2.7	<b>2.6</b>	3.1	9.9	8.0	2.8
	1991	<b>2.6</b>	<b>2.3</b>	3.0	<b>2.3</b>	2.7	2.7	10.9	7.6	2.7
Low income households (%)	2006	<b>20.4</b>	21.5	19.7	<b>21.0</b>	<b>20.1</b>	25.9	13.9	8.5	20.4
	1996	<b>20.0</b>	<b>19.1</b>	20.8	22.9	<b>18.5</b>	23.5	16.6	11.2	19.5

<sup>A</sup>Median values are given instead of means for the percentage of indigenous, rural or remote, and low income households due to the significant range in values.

<sup>B</sup>The definition of rural or remote populations published by the ABS changed in each year. Prior to 2001 this was based on number of dwellings. From 2001 onwards the ARIA index was used.

**Table 3. Comparison of selected Australian health economic indicators for each Australian State and Territory with the eight-jurisdictional average (JA)**

Values in bold are the three Australian States and Territories closest to the jurisdictional average

	Year	NSW	VIC	QLD	SA	WA	TAS	NT	ACT	JA (s.d.)
Available beds <sup>A</sup> (per 1000 population)	2005–06	<b>2.9</b>	2.4	<b>2.5</b>	3.2	<b>2.5</b>	<b>2.7</b>	<b>2.8</b>	2.2	2.7 (0.3)
	2000–01	<b>2.7</b>	<b>2.6</b>	<b>2.8</b>	3.4	2.9	2.3	2.9	2.2	2.7 (0.3)
	1996–97	3.3	2.7	3.3	3.6	<b>2.9</b>	<b>2.8</b>	<b>3.2</b>	2.5	3.0 (0.4)
Health expenditure (\$ per capita)	2005–06	<b>3970</b>	<b>3927</b>	3660	<b>4070</b>	3905	3633	4954	—	4017 (443.2)
	2001–02	<b>2993</b>	<b>3144</b>	2830	<b>2995</b>	2908	3338	3439	—	3092 (225.6)
	1996–97	<b>2161</b>	<b>2176</b>	<b>2104</b>	2037	2008	2410	2442	—	2191 (171.7)
Medicare benefits paid (\$ per capita)	2006	592.8	542.1	<b>528.3</b>	541.0	<b>462.4</b>	<b>479.4</b>	284.8	427.0	488.9 (95.5)
	2001	406.5	385.6	<b>366.9</b>	394.5	<b>336.2</b>	<b>348.8</b>	185.7	313.9	346.6 (70.4)
	1996	357.2	337.2	<b>319.1</b>	324.2	<b>292.6</b>	<b>288.5</b>	177.3	269.7	299.7 (55.6)
PBS and RPBS benefits paid (\$ per capita)	2006	306	<b>299</b>	<b>285</b>	320	<b>252</b>	329	99	224	264 (75.4)
	2001	236	<b>227</b>	<b>221</b>	252	<b>197</b>	260	78	176	206 (58.5)
	1996	149	<b>133</b>	<b>128</b>	139	<b>111</b>	147	43	93	118 (35.6)
	1992	90	<b>73</b>	<b>75</b>	77	<b>61</b>	80	22	48	66 (21.7)
Private health insurance <sup>B</sup> (%)	2006	44.7	<b>42</b>	<b>40.3</b>	43.6	47.4	<b>41.8</b>	30.6	—	41.5 (5.3)
	2001	45.5	<b>44.7</b>	<b>42.4</b>	45.8	48	<b>44.6</b>	34.2	—	43.6 (4.5)
	1996	44.7	<b>42</b>	<b>40.3</b>	43.6	47.4	<b>41.8</b>	30.6	—	41.5 (5.3)
Disabled population <sup>C</sup> (%)	2003	17.7	<b>19.9</b>	<b>22.5</b>	22.6	<b>21.4</b>	22.6	—	15.8	20.4 (2.7)
	1998	<b>19.3</b>	18.0	<b>19.9</b>	22.4	<b>19.5</b>	22.3	—	17.2	19.8 (2.0)

<sup>A</sup>Available public acute and psychiatric hospital beds.

<sup>B</sup>The percentage of the population who are privately insured in the ACT is included in the NSW figure.

<sup>C</sup>The data from the NT regarding disabled persons are considered unreliable for reporting.

The proportions of disabled people across the jurisdictions averaged 20%. WA (19.5–21.4%) and QLD (19.9–22.5%) were closest to the eight-jurisdiction average in all years, whereas the ACT had the lowest proportion of disabled persons (15.8–17.2%).

## Discussion

Large-scale health research involving whole populations has become a practical reality since the introduction of data linkage systems and the techniques needed to analyse their complex linked datasets.<sup>32</sup> Although only a handful exist worldwide,<sup>32–36</sup> their number is growing as evidence of their value in population-based health research has mounted.<sup>2</sup> In Australia, data linkage forms part of the National Collaborative Research Infrastructure Strategy, whereby new data linkage systems in other Australian States and Territories will join those in WA and NSW as part of a national future roadmap for population health research.<sup>37</sup> Consequently, the use of data linkage research infrastructure is only likely to continue to grow within Australia and questions about their external validity will continue to arise.

Our study facilitates comparison of Australia's State and Territory population profiles and helps researchers to determine the extent to which key socio-demographic and health economic indicators may affect the external validity of research arising from any one jurisdiction. We found that despite its isolation and comprising only one-tenth of the Australian population,<sup>1</sup> WA was highly representative of other Australian State and Territory populations, being among the three jurisdictions closest to the eight-jurisdictional average in all but two of the indicators examined (proportion privately insured and per capita health expenditure). In reality, differences in indicators between Australian States other than the proportions of rural and remote residents and people of indigenous origin are relatively minor and the generalisability of research results arising from any Australian State is probably a reasonable presumption.

We found the ACT and NT were the least representative jurisdictions in Australia for most of the socio-demographic and health indicators compared. The NT had the youngest population; the highest proportion of men, indigenous people, low-income families, proportion living in rural or remote areas and rate of out-of-State migration. In terms of its health economic indicators, the NT had the highest per capita health expenditure, lowest uptake of private health insurance and lowest MBS and PBS and RPBS benefits paid. The ACT had the second youngest population and the lowest proportion of indigenous people, rural or remote population, low-income families, and disabled people.

Rural or remote and indigenous populations of Australia are important in health research since they often have poorer access to health services and other resources due to factors such as distance and cultural barriers, which ultimately leads to inequalities in health outcomes.<sup>5,38–40</sup> It could be argued that the NT, TAS and QLD with their larger rural or remote populations are better suited for population-based research involving the health issues that affect them. Similarly, the NT had by far the highest proportion of its population who were

indigenous (1 in 4) making it also better suited to indigenous research.

Out-of-state migration may cause systematic error in population-based studies due to loss-to-follow-up. We found that outward migration was relatively low for most of the Australian States. This was particularly for VIC, SA and WA where levels were less than 2.8% per annum and are low by international standards.<sup>41</sup> Outward migration levels for Australia's Territories were high (10.9 and 8.0% for the NT and ACT respectively), which could lead to erroneous research findings due to loss-to-follow-up.

It should be noted that data presented here are aggregate data sourced from routine publically available documents produced by Australian Government departments, particularly ABS Australian Census data.<sup>10–22</sup> Australian Census data are subject to several known sources of error, including respondent error, processing error, partial responses and under-ascertainment.<sup>42</sup> As such, the accuracy of the information presented is subject to the quality of data reported in these publications. However, with the possible exception of the ascertainment of indigenous status, levels of such error are unlikely to vary much across the Australian jurisdictions.

## Conclusion

We found WA was the most representative of the Australian States and Territories although realistically there is little variation between Australia's jurisdictions for most of the socio-demographic and health economic indicators that we examined. The exceptions to this were for the ACT and NT, which were markedly different to the State jurisdictions, particularly for their rural or remote and indigenous population profiles. In the absence of previous evaluations in this area and with the continued emergence of new data linkage systems around the country, this information is important for health researchers and policy makers who may draw conclusions and make policy decisions that rely upon extrapolating findings from population-based studies.

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## Chapter 3

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# Sight-threatening complications of cataract surgery: a data linkage study

### Research output

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#### Published manuscripts

1. Clark A, Morlet N, Ng JQ, Preen DB, Semmens JB. **Whole population trends in complications of cataract surgery over 22 years in Western Australia.** *Ophthalmology* 2011; 118 (6): 1055-1061.
2. Clark A, Morlet N, Ng JQ, Preen DB, Semmens JB. **Retinal Detachment after phacoemulsification.** *Archives of Ophthalmology* 2012; 130(7):882-8.
3. Clark A, Ng JQ, Morlet N, Semmens JB. **Trends and outcomes of anterior vitrectomy after cataract surgery.** *Acta Ophthalmologica*. 2014; Jun 5 2014 [early view online]

#### Conference presentations

1. Clark A, Morlet N, Ng JQ, Preen DB, Semmens JB. **Significant risk factors for retinal detachment after phacoemulsification: A population-based data linkage study of cataract surgery outcomes in Western Australia over 22 years.** 41<sup>st</sup> Annual Royal Australian and New Zealand College of Ophthalmologists Annual Scientific Conference, Brisbane, Australia, November 2009 (Free paper)
2. Clark A, Morlet N, Ng JQ, Preen DB, Semmens JB. **The risk profile of major sight-threatening complications of cataract surgery: a population-based data linkage study of cataract surgery outcomes in Western Australia over 22 years.** 41<sup>st</sup> Annual Royal Australian and New Zealand College of Ophthalmologists Annual Scientific Conference, Brisbane, Australia, November 2009 (Free paper)
3. Clark A, Morlet N, Ng JQ, Preen DB, Semmens JB. **Trends and outcomes of anterior vitrectomy during cataract surgery: a population-based data linkage study of cataract surgery outcomes in WA over 22yrs.** 41<sup>st</sup> Annual Royal Australian and New Zealand College of Ophthalmologists Annual Scientific Conference, Brisbane, Australia, November 2009 (poster)
4. Clark A, Ng JQ, Morlet N, Semmens JB. **Trends in the major sight threatening complications of cataract surgery in Western Australia 1980 to 2001.** 41<sup>st</sup> Annual Royal Australian and New Zealand College of Ophthalmologists Annual Scientific Conference, Brisbane, Australia, November 2009 (poster)
5. Clark A, Morlet N, Ng JQ, Semmens J. **Cataract Surgery Outcomes in Western Australia: a whole-population study 1980 to 2001.** Royal Australian and New Zealand College of Ophthalmologists (WA Branch), Western Australia Meeting 2009. Margaret River, Western Australia, February 2009. (Invited speaker)
6. Clark A, Ng JQ, Morlet N, Semmens JB. **Complications After Cataract Surgery in Western Australia 1980 to 2000.** 37<sup>th</sup> Annual Royal Australian and New Zealand College of Ophthalmologists Annual Scientific Conference, Perth, Australia, November 2007 (Free paper)



### 3.1. Background

Modern cataract surgery has undergone several transformations over the last three decades from intracapsular (ICCE) to extracapsular extraction (ECCE) with IOL in the late 1970s, to small incision phacoemulsification with foldable IOL during the late 1980s, and then to sutureless phacoemulsification in the 1990s.<sup>130,131</sup> The transition away from ICCE has been associated with improved outcomes,<sup>239,240</sup> although it is unclear whether the same can be said for the transition to phacoemulsification. The introduction of phacoemulsification has, however, contributed to reduced operating and patient recovery time, making modern same-day outpatient cataract surgery a reality.<sup>241</sup> The result has been an exponential increase in cataract surgery rates in most developed countries such that it has become one of the most common surgical procedures performed today.<sup>130,131</sup>

While major complications of cataract surgery remain uncommon,<sup>28</sup> even rare complications have the potential to cause considerable visual burden in the community where large volumes of surgery are performed.<sup>242</sup> Retinal detachment, dropped nucleus (retained lens fragments), corneal decompensation, IOL dislocation, wound dehiscence, and postoperative endophthalmitis are serious complications of cataract surgery that cause severe, potentially permanent, visual morbidity that often requires costly intervention.

The serious complications examined in this thesis were retinal detachment, pseudophakic corneal oedema, IOL dislocation, dropped nucleus (retained lens fragments), and wound dehiscence. This list is by no means exhaustive since other sight-threatening complications may occur e.g. cystoid macular oedema, suprachoroidal haemorrhage, and posterior capsule opacification. However, they were chosen specifically since a) they encompass the most common of the sight-threatening cataract surgery complications; and b) they all require a hospital admission and surgery in order to treat them (and thus a HMDC record). Other complications such as cystoid macular oedema and posterior capsule opacification, whilst important, are generally treated on an outpatient basis and not identifiable within the HMDC.

**Table 1** - Previously published rates of retinal detachment after cataract surgery.

Author(s)	Location	Time period	Number of procedures	Incidence (%)	Follow-up time
<b>Population-based studies</b>					
Sheu <i>et al</i> (2007) <sup>243</sup>	Taiwan	1999 – 2001	9,388	1.16	6 yrs
Erie <i>et al</i> (2006) <sup>84</sup>	USA	1980 – 2004	10,256	0.71	5 yrs
Norregaard <i>et al</i> (1996) <sup>244</sup>	Denmark	1985 – 1987	10,493	0.93	4 yrs
Ninn-Pedersen and Bauer (1996) <sup>245</sup>	Sweden	1986-1990	5,878	0.18	2 yrs
Javitt <i>et al</i> (1994) <sup>167</sup>	USA	1986 - 1988	57,103	0.81	3 yrs
Javitt <i>et al</i> (1991) <sup>171</sup>	USA	1984	338,141	0.9 – 1.55	4 yrs
Stark (1983) <sup>246</sup>	USA	1978 – 1982	11,428	0.6	12-14 mths
<b>Multi-centre studies</b>					
Norregaard (1999) <sup>242</sup>	USA Denmark Manitoba Barcelona	1991 - 1993	1,349	0.1	48hrs
Desai <i>et al</i> (1999) <sup>247</sup>	UK	1997	15,787	0.165	3 mths
Desai (1993) <sup>248</sup>	UK	1990	998	0.1	3 mths
Khatibi <i>et al</i> (2008) <sup>249</sup>	USA	1996 – 2005	4,501	0.76	Up to 10yrs
<b>Single-centre studies</b>					
Nielsen & Naeser (1993) <sup>250</sup>	Denmark		1,726	0.41	~39 mths
Naeser <i>et al</i> (1998) <sup>251</sup>	Denmark	1984 – 1986	1,041	2.8	10 yrs
Russell <i>et al</i> (2006) <sup>252</sup>	New Zealand	1992 – 1993	1,793	1.17	10 yrs
Boberg-Ans <i>et al</i> (2006) <sup>172</sup>	Denmark	1996 – 1998	6,352	0.93	8 yrs
Tuft <i>et al</i> (2006) <sup>253</sup>	UK	1994 - 2003	63,298	0.41	Up to 10 yrs
Coonan <i>et al</i> (1985) <sup>254</sup>	USA	1973 - 1983	842	1.4	Up to 10 yrs
Chitkara & Smerdon (1997) <sup>255</sup>	UK	1987 - 1991	1,552	0.3	Up to 4 yrs
Percival <i>et al</i> (1983) <sup>256</sup>	UK	1972 – 1981	1,324	0.8 - 3.6	Up to 10yrs
Ripandelli <i>et al</i> (2007) <sup>257</sup>	Italy	1997 - 1999	453	3.1	5 yrs
Alio <i>et al</i> (2007) <sup>258</sup>	Spain	1996 – 2000	439	3.3	5 yrs
Allredge <i>et al</i> (1998) <sup>259</sup>	USA		80	0	Up to 6 yrs
Olsen & Olson (2000) <sup>260</sup>	USA	1976 – 1997	2,739	0.4 – 5.4	Up to 22 yrs
Szijaártó <i>et al</i> (2007) <sup>261</sup>	Hungary	1994 - 2004	11,098	0.36	Up to 10 yrs
Bhagat <i>et al</i> (2007) <sup>262</sup>	USA	2000 – 2005	755	0.1	Intra-operative
Haargaard <i>et al</i> (2008) <sup>263</sup>	Denmark	1977 – 2001	1,138	2.3	
Stark <i>et al</i> (1983) <sup>246</sup>	USA	1975 - 1983	1,344	0.8 – 3.5	3 – 76 mths
Smith <i>et al</i> (1987) <sup>264</sup>	USA	1978 – 1986	2,330	1.7	12 mths
Zaidi <i>et al</i> (2006) <sup>265</sup>	UK	2002 – 2004	1,000	0.2	2 weeks
Monica (2005) <sup>266</sup>	USA	1994 – 2003	3,500	0.17	5 yrs
Holland <i>et al</i> (1992) <sup>267</sup>	USA	1983 - 1986	600	1.7	> 6 mths
Riley <i>et al</i> (2002) <sup>268</sup>	New Zealand	2000	476	0	1 mth
Ozbek <i>et al</i> (2007) <sup>269</sup>	Turkey	1999 – 2006	414	1.9	4 – 92 mths

The reported incidence of these complications varies considerably:

- Retinal detachment can occur either as a primary complication of cataract surgery or as a result of other adverse events such as dropped nucleus. It may affect up to 5.4% of cataract surgery patients depending on the year of surgery and procedure type (Table 1). Risk factors that have been identified include a younger age at the time of operation, surgery complicated by posterior capsule rupture, axial myopia and subsequent Nd:YAG laser capsulotomy.<sup>84,167,172,243,244,246,251,252,255,261,264</sup>
- Pseudophakic corneal oedema typically requires expensive corneal transplantation to achieve optimal visual outcomes. It may occur many years following surgery and so many of the studies of its incidence are limited by short follow-up time (Table 2). The reported incidence also varies widely in studies (0-5.3%), reflecting the varying follow-up times and surgical procedure types.
- IOL dislocations may occur anytime postoperatively and typically requires surgery i.e. IOL repositioning or exchange. Most reports of its incidence are from case reports with relatively little known of the true incidence. The handful of studies are limited by short follow-up with most reporting only early post-operative events (Table 3).
- Wound dehiscence incidence varies widely in reports, largely due to differences in procedure type (Table 4).
- Dropped nucleus is more common in many countries since phacoemulsification was introduced (Table 5). Up to 37% of patients with a dropped nucleus may be left with poor residual vision.<sup>270,271</sup> There are currently no reports of sufficient duration to examine how its incidence has changed over time.
- Postoperative endophthalmitis following cataract surgery accounts for around 60-70% of all cases of endophthalmitis. This complication was the focus of the Endophthalmitis Population Study of WA (EPSWA) that preceded this thesis. EPSWA found that endophthalmitis causes blindness or severe visual impairment in 70% of affected patients,<sup>272</sup>

occurs in as many as one in five hundred cataract cases (25-30 cases a year in WA) (Table 6), and has increased in parallel with the 6% annual increase in cataract surgery over the last 20 years.<sup>95</sup>

Most previous studies of cataract surgery complications involved a single center or small groups of surgeons and were adversely affected by small sample sizes or short follow-up. Low case numbers complicate statistical comparisons, while short follow-up makes it difficult to examine trends over time, particularly the impact of changing surgical technique. The low incidence of complications makes population-based longitudinal studies using hospital administrative data the best model to evaluate surgical outcomes and complications of cataract surgery.

## **3.2. General methods**

The methods used to identify and validate the cataract surgery cohort and those who had a subsequent major sight-threatening complication for this thesis are herein described. Specific methods relating to data analysis and subgroup analysis pertinent to individual papers are outlined in detail in the relevant papers.

### **3.2.1. Data source**

In WA all cataract surgery can only be performed in health facilities licensed with the WA Department of Health. It is incumbent upon these facilities to provide the WA Department of Health with data from all admissions, including same-day admissions. Data provided includes patient demographics, co-morbidities, primary and secondary diagnoses, and any procedures undertaken or complications arising during the admission recorded at discharge. This data encompassing all admissions from all WA hospitals (public and private) forms the Hospital Morbidity Data Collection (HMDC); one of the core data sets of the WADLS.

### **3.2.2. Linked data extraction**

The WADLS was used to extract hospital discharge data from the HMDC for all patients who underwent surgery for cataract extraction or a lens-related procedure during 1980 to 2001.

**Table 2** – Previously published rates of pseudophakic corneal oedema.

Author(s)	Location	Time period	Number of procedures	Incidence (%)	Follow-up time
<b>Population-based studies</b>					
Canner <i>et al</i> (1992) <sup>180</sup>	USA	1984	338,141	0.52 – 1.02	4 yrs
Stark <i>et al</i> (1983) <sup>246</sup>	USA	1978 – 1982	11,428	0.1	12 - 14 mths
<b>Multi-centre studies</b>					
Jaycock <i>et al</i> (2009) <sup>28</sup>	UK	2001 – 2006	16,731	5.18	31 days
Desai (1993) <sup>248</sup>	UK	1990	998	0.4	3 mths
<b>Single-centre studies</b>					
Zaidi <i>et al</i> (2006) <sup>265</sup>	UK	2002 – 2004	1,000	0.7	2 weeks
Monica (2005) <sup>266</sup>	USA	1994 – 2003	3,500	0	5 yrs
Chitkara & Smerdon (1997) <sup>255</sup>	UK	1987 - 1991	1,552	0.06	Up to 4 yrs
Holland <i>et al</i> (1992) <sup>267</sup>	USA	1983 - 1986	600	0.33	> 6 mths
Stark <i>et al</i> (1983) <sup>246</sup>	USA	1975 – 1983	1,344	0.1	76 mths
Riley <i>et al</i> (2002) <sup>268</sup>	New Zealand	2000	476	0.4	1 mth
Wegener <i>et al</i> (1998) <sup>273</sup>	Denmark	1994 - 1995	951	0.1	-
Baggensen & Ehlers (1997) <sup>274</sup>	Denmark	1986 – 1988	2455	5.3	5 – 7 yrs
Naeser <i>et al</i> (1998) <sup>251</sup>	Denmark	1984 – 1986	1,041	2.3	10 yrs

**Table 3** – Previously published rates of IOL dislocation after cataract surgery.

Author(s)	Location	Time period	Number of procedures	Incidence (%)	Follow-up time
<b>Multi-centre studies</b>					
Norregaard (1999) <sup>242</sup>	USA Denmark Manitoba Barcelona	1991 - 1993	1,349	0.2	48hrs
Desai (1993) <sup>248</sup>	UK	1990	998	0.3	3 mths
Stark <i>et al</i> (1983) <sup>246</sup>	USA	1978 – 1982	11,428	0.5	12-14 mths
Jaycock <i>et al</i> (2009) <sup>28</sup>	UK	2001 – 2006	16,731	0.22	31 days
Desai <i>et al</i> (1999) <sup>247</sup>	UK	1997	17,257	0.1	48hrs post op
<b>Single-centre studies</b>					
Jin <i>et al</i> (2005) <sup>275</sup>	USA	1998 – 2004	6,630	0.29	> 3 mths
Stark <i>et al</i> (1983) <sup>246</sup>	USA	1975 - 1983	1,344	0.3 -6.0	3 – 76 mths
Riley <i>et al</i> (2002) <sup>268</sup>	New Zealand	2000	483	0.41	Day 1
Ozbek <i>et al</i> (2007) <sup>269</sup>	Turkey	1999 – 2006	414	0	4 – 92 mths
Wegener <i>et al</i> (1998) <sup>273</sup>	Denmark	1994 - 1995	951	0.4	-
Rutar <i>et al</i> (2009) <sup>276</sup>	USA	2006 - 2007	320	0.62	90 days
Chitkara & Smerdon (1997) <sup>255</sup>	UK	1987 - 1991	1,552	0	Up to 4 yrs

**Table 4** – Previously published rates of wound dehiscence after cataract surgery.

Author(s)	Location	Time period	Number of procedures	Incidence (%)	Follow-up time
<b>Multi-centre studies</b>					
Jaycock <i>et al</i> (2009) <sup>28</sup>	UK	2001 – 2006	16,731	0.14	31 days
Norregaard (1999) <sup>242</sup>	USA	1991 - 1993	1,349	0.4	48hrs
	Denmark				
	Manitoba				
	Barcelona				
Desai (1993) <sup>248</sup>	UK	1990	998	0.4	3 mths
Desai <i>et al</i> (1999) <sup>247</sup>	UK	1997	17,257	1.2	48hrs post op
<b>Single-centre studies</b>					
Zaidi (2006) <sup>265</sup>	UK	2002 – 2004	1,000	1.1	2 weeks
Monica (2005) <sup>266</sup>	USA	1994 – 2003	3,500	0	5 yrs
Ball & McCleod (2001) <sup>277</sup>	UK	1986 – 1993, 1996 -1998	9,800	0.22	
Quraishy & Casswell (1996) <sup>278</sup>	UK	1986 – 1993	~5,600	~0.37	
Holland <i>et al</i> (1992) <sup>267</sup>	USA	1983 – 1986	600	0.33	> 6 mths
Riley <i>et al</i> (2002) <sup>268</sup>	New Zealand	2000	483	1.9	Day 1
Rutar <i>et al</i> (2009) <sup>276</sup>	USA	2006 - 2007	320	0.3	90 days
Arango & Margo (1998) <sup>279</sup>	USA	1988 – 1996	2,041	1.5	3 mths
Naeser <i>et al</i> (1998) <sup>251</sup>	Denmark	1984 – 1986	1,041	2.1	10 yrs
Chitkara & Smerdon (1997) <sup>255</sup>	UK	1987 - 1991	1,552	1.3	4mths - 4 yrs

**Table 5** – Previously published rates of dropped nucleus during cataract surgery.

Author(s)	Location	Time period	Number of procedures	Incidence (%)
<b>Multi-centre studies</b>				
Norregaard (1999) <sup>242</sup>	USA	1991 - 1993	1,349	0.3
	Denmark			
	Manitoba			
	Barcelona			
Jaycock <i>et al</i> (2009) <sup>28</sup>	UK	2001 – 2006	55,567	0.18
Misra & Burton (2005) <sup>280</sup>	UK	2002 – 2003	1,883	0.11
Stilma <i>et al</i> (1997) <sup>270</sup>	Netherlands	1992 – 1994	41,460 – 52,788	0.09 – 0.9
Desai <i>et al</i> (1999) <sup>247</sup>	UK	1997	17,257	0.3
<b>Single-centre studies</b>				
Zaidi (2006) <sup>265</sup>	UK	2002 – 2004	1,000	0.1
Riley <i>et al</i> (2002) <sup>268</sup>	New Zealand	2000	488	0.8
Rutar <i>et al</i> (2009) <sup>276</sup>	USA	2006 - 2007	320	0.93
Bhagat <i>et al</i> (2007) <sup>262</sup>	USA	2000 – 2005	755	0.97
Seward <i>et al</i> (1993)	UK	1990	400	0.25

**Table 6** – Previously published rates of endophthalmitis after cataract surgery.

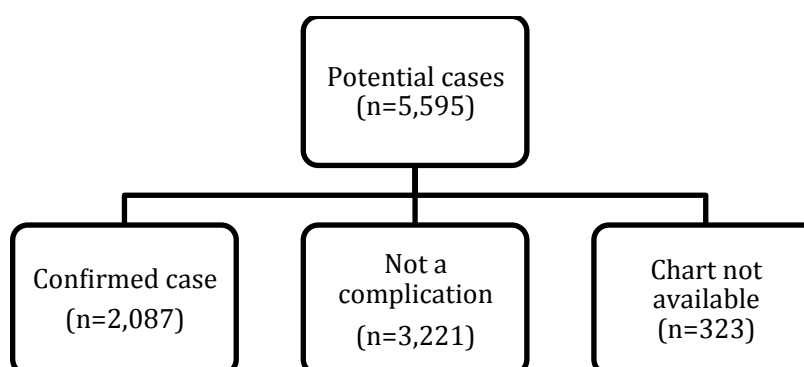
Author(s)	Location	Time period	Number of procedures	Incidence (per 1,000)
<b>Population-based studies</b>				
Montan <i>et al</i> (2002) <sup>281</sup>	Sweden	1998	54,666	1.06
Versteegh <i>et al</i> (2000) <sup>282</sup>	Netherlands	1996-1997	71,028	1.52
Wegener <i>et al</i> (1998) <sup>273</sup>	Denmark	1994-1995	951	0.00
Norregaard <i>et al</i> (1997) <sup>283</sup>	Denmark	1985-1987	19,426	3.14
Javitt <i>et al</i> (1994) <sup>167</sup>	USA	1986-1987	57,103	0.77
Javitt <i>et al</i> (1991) <sup>166</sup>	USA	1984	324,032	1.36
<b>Multi-centre studies</b>				
Norregaard (1999) <sup>242</sup>	USA	1991 - 1993	1,349	0
	Denmark			
	Manitoba			
	Barcelona			
Versteegh <i>et al</i> (2000) <sup>282</sup>	Netherlands	1996-1997	33,750	1.16
Schmitz <i>et al</i> (1999) <sup>284</sup>	Germany	1996	340,633	0.78
Desai <i>et al</i> (1999) <sup>247</sup>	United Kingdom	1997	15,787	1.65
Desai <sup>38</sup> (1993) <sup>248</sup>	United Kingdom	1990 (1 week)	98	3.00
Fisch <i>et al</i> (1991) <sup>285</sup>	France	1988-1989	26,731	3.23
<b>Single-centre studies</b>				
Monica (2005) <sup>266</sup>	USA	1994 – 2003	3,500	0
Mayer <i>et al</i> (2003) <sup>286</sup>	United Kingdom	1991-2001	18,191	1.65
Riley <i>et al</i> (2002) <sup>268</sup>	New Zealand	2000	488	2.05
Eifrig <i>et al</i> (2002) <sup>287</sup>	USA	1995-2001	21,972	0.36
Yorston <i>et al</i> (2002) <sup>288</sup>	Africa	1999	1,800	0.00
Ernest <i>et al</i> (2000) <sup>289</sup>	Czechoslovakia	1990-1999	13,247	2.57
Colleaux <i>et al</i> (2000) <sup>290</sup>	Canada	1994-1998	13,886	0.72
Bohigian (1999) <sup>291</sup>	USA	1985-1996	19,269	0.62
Aaberg <i>et al</i> (1998) <sup>292</sup>	USA	1990-1994	18,530	0.92
Somani <i>et al</i> (1997) <sup>293</sup>	Canada	1989-1996	13,285	2.41
Chitkara <i>et al</i> (1997) <sup>255</sup>	United Kingdom	1987-1991	1,552	1.93
Stanila (1996) <sup>294</sup>	Romania	1990-1995	759	3.95
De Gottrau <i>et al</i> (1994) <sup>295</sup>	Switzerland	1983-1992	6,954	1.15
Kattan <i>et al</i> (1991) <sup>296</sup>	USA	1984-1989	23,625	0.72
Kattan <i>et al</i> (1991) <sup>296</sup>	USA	1976-1982	7,552	0.93
Fahmy (1975) <sup>297</sup>	Denmark	1964-1974	4,498	5.33
Allen <i>et al</i> (1974) <sup>298</sup>	USA	Not stated	36,000	0.86
Christy <i>et al</i> (1973) <sup>299</sup>	Pakistan	1957-1972	77,093	4.96
Bhagat <i>et al</i> (2007) <sup>262</sup>	USA	2000 – 2005	755	0

Data was selected using the time period relevant International Classification of Diseases (ICD) codes for diagnoses and procedures i.e. ICD-9 for 1980-87, ICD-9CM for 1988-98, and ICD-10-AM for 1999 onwards.<sup>300,301</sup> The specific procedures extracted were intracapsular extraction of lens (ICCE), extracapsular extraction of lens (ECCE), phacoemulsification (Phaco), other cataract extraction, and lens-related operations. The specific ICD codes used to identify these procedures are detailed in Table 7.

Each complication was also identified using specific ICD procedure codes (Table 7). Diagnosis codes were not used since preliminary analysis found a reduced number of potential complications were flagged using diagnosis codes only, and no additional benefit was conferred when used in combination with procedure codes (presumably since all admission for the complications examined will involve a surgical procedure). Only those cases that occurred during the same admission as the cataract procedure or after the cataract procedure were considered.

### 3.2.3. Database validation

Validation of coded sight-threatening complications identified in the HMDC was undertaken using medical record review (Figure 3-1). Validation was essential since the HMDC does not code for laterality of procedures and without validation it is impossible to determine accurately whether a complication identified occurred in the same eye as the associated cataract surgery.



**Figure 3-1** Results of chart validation of potential cataract surgery complications in WA.



**Table 7** – International classification of diseases procedural codes used to identify potential post-operative complication after cataract surgery in WA 1980 to 2001.

Item	Procedure codes		
	ICD 9 1980 – 1987	ICD 9 CM 1988 – June 1999	ICD 10AM June 1999 onwards
<b>Procedure Type</b>			
Intracapsular	5-144	13.11, 13.19	42698-00, 42702-00, 42702-01
Extracapsular	5-142, 5-145	13.2, 13.3, 13.51, 13.59	42698-01, 42698-04, 42702-02, 42702-03, 42702-08, 42702-09
Phacoemulsification	-	13.41 - 13.43	42698-02, 42698-03, 42702-04, 42702-05, 42702-06, 42702-07
Lens procedure	5-147, 5-149	13.70, 13.71, 13.72, 13.9	42701-00, 42701-01, 42703, 90077-00
Other cataract extraction	5-146	13.64, 13.65, 13.66, 13.69	42734-00, 42719-00, 42719-02, 42698-05, 42788-00, 42722-00, 42731-00, 42702-10, 42702-11, 42731-01, 42716-00
<b>Complication Type</b>			
Retinal detachment	5-152, 5-153, 5-156	14.3 – 14.59, 14.9	42773-00, 42773-01, 42776-00, 42809-01, 90079-00
Intraocular lens dislocation	5-147, 5-149	13.70, 13.72, 13.8	42701-00, 42701-01, 42703-00, 42704-00, 42704-01, 42710-00, 42713-00
Dropped nucleus	5-149, 5-157	13.9, 14.70 – 14.79	42702-10, 42702-11, 42719-01, 42722-01, 42725-00, 42731-01, 42740-05, 9007-00
Pseudophakic corneal edema	5-113, 5-119, 5-125 5-129	10.44, 10.49, 11.53, 11.6, 11.60, 11.61, 11.62, 11.63, 11.64, 11.69	42659-00, 42653-00, 42671-00, 90064-00, 42632-00, 42638-00, 42653-01, 42656-00, 90067-00, 42551-00, 42551-01, 42551-02, 42554-00,
Wound dehiscence	5-124, 5-126	11.5, 11.51, 11.52, 11.59, 12.83, 12.66	42635-00, 42667-00, 42857-00, 42857-01, 90060-00, 90066-00

There were 5,595 patients identified in the HMDC who had a potential sight-threatening complication of their cataract surgery between January 1980 and December 2001. Chart review was an extensive and time-consuming process that took over 2 years to complete. Each hospital in WA where cataract surgery was performed since 1980 was contacted and approval for review of medical records maintained at their site was obtained. Many records were held in off-site storage due to the long time since surgery was performed which further complicated access to previous surgical notes. Despite these difficulties a high proportion of the potential complications identified were validated (>94%) by chart review (Figure 3-1).

### **3.2.4. Ethics approval**

All work for the complications of cataract surgery project undertaken as part of this thesis was carefully reviewed and approved by the Human Research Ethics Committees at Curtin University of Technology, The Western Australian Department of Health, and each of the hospitals involved in the study. (Appendix 1).

## **3.3. Research output**

### ***Published manuscripts***

This chapter resulted in the publication of three substantial papers in the peer-reviewed ophthalmic literature. The first paper begins with an in-depth overview of the trends in complications over the study period. The second paper explores retinal detachment following modern phacoemulsification cataract extraction and the major associated risk factors. The final paper explores trends in complicated cataract surgery over the study period and how complicated surgery affects the risk of subsequent serious complications.

### ***Conference and media presentations***

Research findings arising from this chapter were presented at local, national and international conferences as free paper talks and poster presentations. The paper describing risk factors for retinal detachment was the subject of a media release in the American Academy of Ophthalmology EyeNet magazine and formed the basis for a continuing medical education article on the internationally regarded MedScape website.

### ***Translational projects***

The data validation process identified a significant shortcoming in our ability to monitor cataract outcomes in WA, and that was the inability to access clinical information in a timely and efficient manner. The lack of coding for laterality in the HMDC is a major barrier as is the lack of operative detail in the database. This severely limits our ability to identify a changing trend for specific adverse events and important operative risk factors important in cataract surgery outcomes without having to perform extensive chart validation that is time consuming and costly. By the time any research findings are available it is likely

to be years after the event. With this in mind we developed a web-based electronic cataract auditing and reporting system – eCAT (Appendix 3). The vision is for this to be used across all public and private facilities in WA and available for data linkage with the HMDC to allow rapid analysis of adverse outcomes, without the need for chart review.

I wrote the grant application for the Australian Government National Eye Health Initiative Demonstration Grants (Round 2) to fund the implementation of this system as a pilot project across the public teaching hospitals in WA (Appendix 4). This was successful in securing AUD\$163,883 inc GST in funding. This project is ongoing (Appendix 3).

### **3.4. Published manuscripts**

**Clark A, Morlet N, Ng JQ, Preen DB, Semmens JB.**  
**Whole population trends in complications of**  
**cataract surgery over 22 years in Western**  
**Australia.** *Ophthalmology* 2011; 118(6):1055-1061.

# Whole Population Trends in Complications of Cataract Surgery over 22 Years in Western Australia

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**Objective:** To examine the trends in major complications of cataract surgery in the Western Australian population over 22 years.

**Design:** Population-based study.

**Participants:** We included 129 982 cataract/lens surgery patients across 46 health facilities.

**Methods:** Using the Western Australian Data Linkage System, we identified all patients who underwent cataract/lens surgery in Western Australia between 1980 and 2001. Complications of interest were identified from those patients admitted to hospital or who underwent unplanned surgery after cataract surgery and were validated by medical record review.

**Main Outcome Measures:** Admission for retinal detachment, dropped nucleus, wound dehiscence, pseudophakic corneal edema, intraocular lens (IOL) dislocation, and postoperative endophthalmitis requiring surgery.

**Results:** There were 129 982 cataract/lens procedures and 2087 (1.6%) complications. Complications fell almost 70% over the study period. Retinal detachment ( $n = 905$ ; 0.70%) was most common, followed by IOL dislocation ( $n = 361$ ; 0.28%), endophthalmitis ( $n = 228$ ; 0.18%), wound dehiscence ( $n = 227$ ; 0.17%), pseudophakic corneal edema ( $n = 207$ ; 0.16%), and dropped nucleus ( $n = 159$ ; 0.12%). The incidence of complications lessened over time, except for IOL dislocations, which has increased since 1995. Overall, the risk of complications after phacoemulsification halved since it was introduced in the late 1990s (incidence rate ratio, 0.52; 95% confidence interval, 0.37–0.74), whereas complications after extracapsular extraction (ECCE) have increased over recent years.

**Conclusions:** Cataract surgery remains an extremely safe procedure with comparatively few major complications. Changes in operative techniques have been accompanied by a significant decrease in complication rates over time, although the increase in IOL dislocations and complications after ECCE warrants further study.

**Financial Disclosure(s):** The authors have no proprietary or commercial interest in any of the materials discussed in this article. *Ophthalmology* 2011;118:1055–1061 © 2011 by the American Academy of Ophthalmology.



Modern cataract surgery technique has changed significantly over the last 30 years from intracapsular (ICCE) to extracapsular extraction (ECCE) with intraocular lens (IOL) in the late 1970s, to small incision phacoemulsification during the late 1980s, followed by the adoption of sutureless phacoemulsification with foldable IOL in the 1990s.<sup>1,2</sup> The transition to phacoemulsification is credited with reducing operating and patient recovery times and paving the way for same-day, outpatient cataract surgery.<sup>3</sup> Although the transition away from ICCE was associated with fewer complications, it remains unclear whether phacoemulsification is safer than ECCE.

Cataract surgery is the most commonly performed operative procedure today,<sup>1,2</sup> with few complications.<sup>4</sup> However, when large volumes are involved, even rare complications of cataract surgery have the potential to cause considerable visual burden in the community. Major complications include retinal detachment, postoperative endophthalmitis, IOL dislocation,

pseudophakic corneal edema, dropped nucleus (retained lens fragments), and wound dehiscence. The reported incidence of these complications varies considerably.<sup>1,4–27</sup> Both retinal detachment and postoperative endophthalmitis are well characterized in population-based studies. The incidence of retinal detachment from these studies ranged between 0.6% and 1.5%, depending on year and procedure type,<sup>5–15</sup> whereas postoperative endophthalmitis ranged between 0.1% and 0.3%.<sup>1,16,17</sup> The incidence of IOL dislocation is reported as 0.2% to 6.0%, although most studies are case reports or have follow-up limited only to early postoperative events.<sup>4,9,18–21,28</sup> Similarly, the reported incidence of pseudophakic corneal edema (0%–5.2%)<sup>4,9,12,19,22,23</sup> is limited in many studies by short follow-up time. Dropped nucleus is more common in many countries since the introduction of phacoemulsification, with studies reporting an incidence of 0.1 to 0.3%.<sup>4,18,22,24,25</sup> Wound dehiscence rates also vary

widely (0%–2.1%), largely owing to differences in procedure type and classification.<sup>4,15,18,19,22,23,26,27</sup>

Most previous studies of cataract surgery complications involved a single center or small groups of surgeons and were adversely affected by small sample sizes or short follow-up. Low case numbers complicate statistical comparisons, and short follow-up makes it difficult to examine trends over time, particularly the impact of changing operative techniques. The low incidence of complications makes population-based longitudinal studies the best model to evaluate surgical outcomes and complications of cataract surgery. Our aim was to examine the trends of some important complications of cataract surgery in the entire Western Australian population over 22 years. This is the first report in a series to examine the trends and characteristics of the major complications of cataract surgery in Western Australia.

## Methods

We conducted a whole-population, retrospective, longitudinal study of clinically important complications of cataract and lens surgery from 1980 to 2001 using linked administrative data from the Western Australian Data Linkage System. Specifically, we examined retinal detachment, IOL dislocation, pseudophakic corneal edema, dropped nucleus, endophthalmitis, and wound dehiscence. We previously reported the trends in the incidence of endophthalmitis after cataract surgery in Western Australian from 1980 to 2000, and present the additional cases from 2001.

## Data Source

Cataract surgery in Western Australia may only be performed in health facilities licensed by the Western Australian Department of Health. These facilities must provide the Western Australian Department of Health with data from all admissions, including same-day admissions. The data routinely recorded at discharge include patient demographics, comorbidities, primary and secondary diagnoses, and any procedures undertaken or complications arising during the admission. These data, encompassing all admissions from all Western Australian hospitals (public and private), form the Hospital Morbidity Data Collection (HMDC), which is one of the core data sets of the Western Australian Data Linkage System.<sup>29</sup>

We used the Western Australian Data Linkage System to extract hospital discharge data from the HMDC for all patients who underwent cataract extraction or a lens procedure from 1980 to 2001. These data were linked to the State Mortality Register and allowed us to account for loss to follow-up because of death. Data were coded using the relevant International Classification of Diseases (ICD) codes for diagnoses and procedures (ICD-9 for 1980–87, ICD-9CM for 1988–98, and ICD-10-AM for 1999 onwards).<sup>30,31</sup> The procedures extracted included ICCE, ECCE, phacoemulsification, “other” cataract extraction, and lens operations (Table 1; available online at <http://aaojournal.org>).

## Identification of Complications

Only complications that required hospital admission or surgical treatment (necessitating hospital admission) were considered cases because they were more likely to be reliably identified in the HMDC. Additionally, these cases were more likely to be vision threatening or clinically important. Complications (except endo-

phthalmitis) were identified using ICD procedure codes detailed in Table 1 (available online at <http://aaojournal.org>). Except for endophthalmitis, diagnosis codes were not used because preliminary analysis found a reduced number of potential complications were identified using diagnosis codes only. No additional benefit was conferred by diagnosis codes used in combination with procedure codes because all admissions for the complications examined involve an operative procedure. Only those complications that occurred during or after the same admission as the cataract procedure were considered cases. The method of selecting and validating the endophthalmitis cohort was different to that of the other complications and has been described elsewhere.<sup>1,32,33</sup>

## Data Validation

There were 6286 potential cases identified within the HMDC dataset. Each case was validated by hospital record review to confirm the type of complication and that the complication occurred in the same eye as the associated cataract/lens procedure (laterality is not recorded in the HMDC). For all confirmed cases, we also recorded important operative information about the cataract operation such as procedure type, IOL insertion, IOL type, and other concurrent procedures. We were unable to validate 363 (5.8%) potential cases because the required hospital record was unavailable or it was not possible to accurately confirm whether a true complication occurred. These were excluded from analysis.

Although desirable, it was not logistically possible to obtain information regarding patient’s preoperative ocular status, such as cataract type, that would allow patient stratification into low- and high-risk groups for further analysis. This is because such variables are not routinely collected within the HMDC dataset.

## Statistical Analysis

Descriptive analysis was performed to characterize the cataract surgery patient cohort and those who had a complication of interest. Using univariate analyses, the annual incidence rate of each complication was calculated as the crude incidence per 1000 procedures. Because of the impact of differing follow-up times for late complications, trends in the incidence of each complication were analyzed differently depending on whether they tended to occur intraoperatively, in the early postoperative period (within the first 3 months after surgery), or later in the postoperative period. For intraoperative and early postoperative complications (dropped nucleus, wound dehiscence, and endophthalmitis) the incidence rate per 1000 procedures was calculated for each 5-year period and the incidence rate ratio comparing each subsequent time period was calculated using Poisson regression adjusting for age and gender.

We used survival analysis to compare the time to event as the cumulative incidence for each late complication (retinal detachment, IOL dislocation, and pseudophakic corneal edema) in each 5-year period. Using Cox proportional hazards regression adjusted for age and gender, we calculated the hazard ratio and 95% confidence intervals (CI), comparing the hazard rate for each complication in each subsequent time period. This allowed us to take into account the differences in follow-up time and censoring of patients. All statistical analysis was performed using STATA 10.0 (StataCorp, College Station, TX); all standard errors were adjusted for clustering of procedures around individuals using generalized estimating equations.

## Ethical Considerations

This study was approved by the Human Research Ethics Committees at Curtin University of Technology, The Western Australian

Department of Health, and each of the hospitals involved in the study. All data analysis was carried out on deidentified data. Identifying patient information was provided only for potential cases for the purposes of data validation and subsequently destroyed upon completion of data validation.

## Results

There were 129 082 cataract/lens procedures performed across 46 health care facilities in Western Australia between 1980 and 2001 (Table 2; available online at <http://aaojournal.org>). The majority ( $n = 69\,575$ ; 53.9%) were performed from 1995 to 2001, with phacoemulsification the most commonly performed operation ( $n = 65\,061$ ; 50.1%) followed by ECCE ( $n = 47\,868$ ; 36.8%), “other”/lens procedures ( $n = 11\,899$ ; 9.2%) and ICCE ( $n = 5153$ ; 4.0%). Females accounted for 58% of the cohort and most patients ( $n = 90\,744$ ; 70.3%) were aged  $\geq 70$  years. Just over half ( $n = 69\,317$ ; 53.7%) of the procedures were performed in the private sector and the majority ( $n = 117\,077$ ; 90.7%) in metropolitan areas. Average length of follow-up was 6.6 years (SD, 5.0; range, 0–22.4).

There were 2087 (1.6%) confirmed complications. The most frequent complication was retinal detachment ( $n = 905$ ; 0.7%), followed by IOL dislocation ( $n = 361$ ; 0.28%), endophthalmitis ( $n = 228$ ; 0.18%), wound dehiscence ( $n = 227$ ; 0.17%), pseudophakic corneal edema ( $n = 207$ ; 0.16%), and dropped nucleus ( $n = 159$ ; 0.12%). Complications were almost twice as common for men than women (2.06% vs 1.28%;  $P < 0.001$ ). This trend was seen with retinal detachment (1.02% vs 0.46%;  $P < 0.001$ ), IOL dislocation (0.37% vs 0.21%;  $P < 0.001$ ), wound dehiscence (0.21% vs 0.15%;  $P = 0.003$ ), and dropped nucleus (0.15% vs 0.10%;  $P = 0.014$ ).

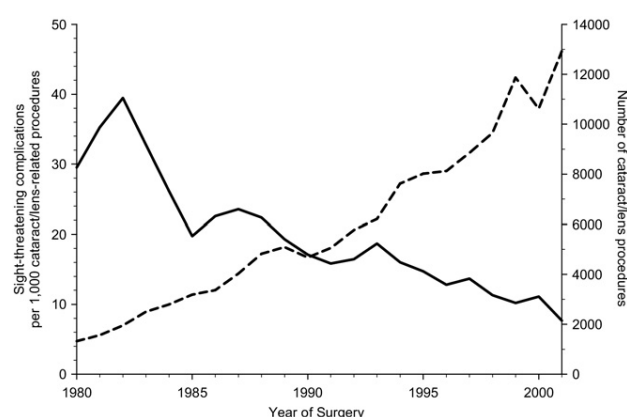
Complications also varied across 10-year age groups. Retinal detachments were more common with decreasing age, whereas cases of IOL dislocation, corneal edema, and dropped nucleus were more common with increasing age. There was no difference in the incidence of wound dehiscence or endophthalmitis over the 10-year age groups. Complications were most common for ICCE and ECCE procedure types (approximately 2%), whereas complications were half as common after phacoemulsification (2% vs 0.98%;  $P < 0.001$ ).

## Trends over Time

The overall incidence of major cataract surgery complications steadily declined over the study period (Fig 1). This was most evident for corneal transplant for pseudophakic corneal edema, which fell by 48% for every 5 years since 1980 (5-year RR, 0.52; 95% CI, 0.44–0.61;  $P < 0.001$ ); retinal detachment, which has fallen by 20% every 5 years since 1980 (5-year RR, 0.80; 95% CI, 0.75–0.85;  $P < 0.001$ ), and wound dehiscence (5-year RR, 0.76; 95% CI, 0.68–0.85;  $P < 0.001$ ; Table 3). There was no significant change in the incidence of endophthalmitis over the study period. The incidence of dropped nucleus increased from a negligible rate pre-1990 to 1.87 per 1000 procedures during 1995 to 2001 (5-year RR, 1.74; 95% CI, 1.16–2.63;  $P = 0.008$ ). The 5-year cumulative incidence of IOL dislocations improved initially (declining from a peak of 0.55% in 1980–1984 to 0.17%–0.18% in 1985–1994), but increased to 0.30% in 1995 to 2001.

## Extracapsular Extraction versus Phacoemulsification

The incidence of all complications except dropped nucleus was generally lower for phacoemulsification compared with ECCE



**Figure 1.** Trend in cataract/lens surgery (---) and the incidence of major complications (dropped nucleus, wound dehiscence, retinal detachment, intraocular lens dislocation, endophthalmitis and pseudophakic corneal edema) per 1000 procedures (—) in Western Australia (1980–2001).

(Fig 2). However, after adjusting for age, sex gender, and year of surgery, only IOL dislocations (RR, 0.47; 95% CI, 0.35–0.63) and wound dehiscence (RR, 0.12; 95% CI, 0.08–0.18) were significantly different (Table 2; available online at <http://aaojournal.org>).

Compared with ECCE, the rate of complications after phacoemulsification consistently improved over the study period (Table 4). Over a similar transition period, complications for ECCE initially fell to a low during the midtransition period, but then increased slightly. This trend was particularly evident for retinal detachment, IOL dislocation, wound dehiscence, and dropped nucleus (Fig 2).

## Discussion

The rate of complications after cataract surgery in Western Australia fell by almost 70% from a peak of 3% in the early 1980s to 1% per annum by 2001. A direct comparison of our results with other published studies is difficult because of a lack of consistency in categorizing complications and because most previous investigations reported only intraoperative and early postoperative events without considering long-term complications.

The greatest decrease over the study period was seen for retinal detachment and pseudophakic corneal edema. Retinal detachment was the most common complication and had a 5-year cumulative incidence of 0.63%. This was similar to a previous study from Olmstead County that also used population-based record linkage methodology. The researchers reported the 5-year cumulative incidence of retinal detachment after cataract surgery between 1980 and 2004 was 0.71%, increasing to 1.79% after 20 years.<sup>6</sup> However, there are no studies that have reported the change in incidence over an extended time. Our findings support the findings of previous studies<sup>5,6,34</sup> that the risk of retinal detachment after phacoemulsification was no greater than for ECCE.

We observed a substantial decline in the rate of pseudophakic corneal edema requiring corneal transplant over the study period. The crude rate after phacoemulsification was 85% less



Table 3. Trend in Overall Incidence of the Major Complications of Cataract/lens Surgery in Western Australia 1980 to 2001

(A) Intraoperative and early post-operative complications (per 1,000 cataract/lens procedures)								
	1980–1984	1985–1989	1990–1994	1995–2001	All years	IRR*	95% CI	P-value
Endophthalmitis	2.17 (1.36–3.29)	1.61 (1.11–2.26)	1.91 (1.44–2.48)	1.66 (1.37–1.99)	1.75 (1.53–1.99)	0.94	(0.82–1.07)	0.33
Wound dehiscence	2.57 (1.68–3.76)	2.63 (1.98–3.44)	2.01 (1.53–2.60)	1.26 (1.00–1.55)	1.75 (1.53–1.99)	0.76	(0.68–0.85)	<0.001
Dropped nucleus	N/A	N/A	1.06 (0.71–1.54)	1.87 (1.56–2.22)	1.31 (1.11–1.53)	1.74	(1.16–2.63)	0.008
(B) Late post-operative complications (5-year cumulative incidence (%))								
	1980–1984	1985–1989	1990–1994	1995–2001	All years	HR†	(95% CI)	P-value
Retinal detachment	1.05 (0.87–1.28)	0.85 (0.72–0.98)	0.60 (0.52–0.69)	0.45 (0.39–0.52)	0.63 (0.58–0.68)	0.80	(0.75–0.85)	<0.001
IOL dislocation	0.55 (0.37–0.80)	0.17 (0.12–0.24)	0.18 (0.14–0.24)	0.30 (0.26–0.34)	0.26 (0.23–0.29)	1.07	(0.92–1.23)	0.39
Pseudophakic corneal edema	0.28 (0.19–0.41)	0.12 (0.08–0.18)	0.09 (0.06–0.13)	0.05 (0.03–0.08)	0.10 (0.08–0.12)	0.52	(0.44–0.61)	<0.001

N/A = not applicable; IOL = intraocular lens.

Numbers in brackets are 95% confidence intervals (CI).

\*Age and sex adjusted incidence rate ratio (IRR) and 95% CI of a complication in each 5-year group after 1980.

†Age and sex adjusted hazard ratio (HR) and 95% CI of a complication in each 5-year group after 1980.

than after ECCE although, with only 20 cases after phacoemulsification, we were not able to confirm a significant difference. To our knowledge, there are no studies that have reported on the change in the incidence of pseudophakic corneal edema with which we can compare our results. Canner et al<sup>35</sup> reported the rate of re-hospitalization for corneal edema or transplant in a single cohort of 325 348 cataract procedures performed in 1984 was 1.06%, 0.52% and, 0.55% for ICCE, ECCE, and phacoemulsification procedures, respectively, and 0.68% overall. Although we found similar results during the same period (early 1980s), the rate of corneal transplantation for pseudophakic corneal edema has dramatically declined since that time. Studies reporting on the trend in the crude number of corneal transplants performed for pseudophakic corneal edema are conflicting with reports of increasing and decreasing trends.<sup>36,37</sup> It is not possible to ascertain whether these numbers relate to an increase or decrease in the actual incidence per cataract procedure. The decline in cases of pseudophakic corneal edema undergoing corneal transplantation in Western Australia is likely multifactorial. Significant improvements in operative techniques, instrumentation, IOL design, and viscoelastics used in cataract surgery have occurred over the study period, all of which act to reduce corneal endothelial damage.<sup>38</sup> Additionally, follow-up time after phacoemulsification was shorter than for ECCE and ICCE, leading to fewer cases being counted and to an underestimation of the true incidence.

The transition to phacoemulsification had a significant impact on the rate of wound dehiscence, which halved over the study period in line with the introduction of small incision surgery. Our procedure-specific rate of wound dehiscence is similar to previous reports,<sup>4,18,19,22,23,26</sup> demonstrating the safety of small incision cataract surgery over ICCE and ECCE at approximately one tenth the rate of wound dehiscence.

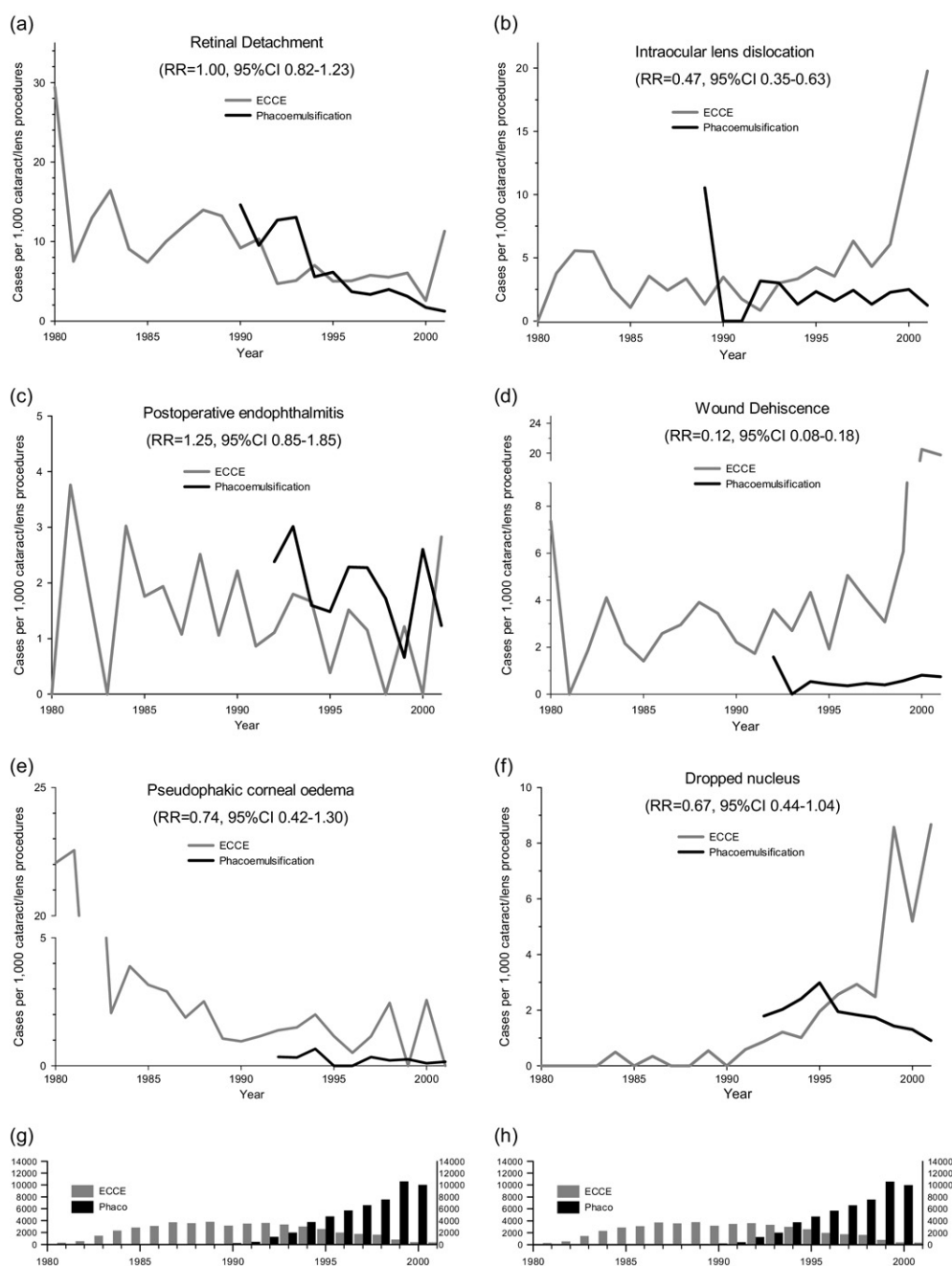
Phacoemulsification was also associated with a dramatic increase in the incidence of dropped nucleus from negligible rates before 1990. The number in our study (0.12%) was low compared with most previous studies, which have re-

ported rates between 0.09% and 0.97%.<sup>4,18,22,24,25</sup> The subsequent decline in the incidence of dropped nucleus found in our study has not been described previously and may be due to a combination of surgeon learning curve and improvements in phacoemulsification operating technique and equipment.

In this study, IOL dislocations have almost doubled since 1985 to a 5-year cumulative incidence of 0.30% in 1995 to 2001. Early reports elsewhere are similar.<sup>39,40</sup> A Swedish study of cataract surgeries in a single center between 2000 and 2005 found that the number of secondary IOL operations had tripled, whereas the number of cataract surgeries had only doubled.<sup>39</sup> Most eyes with IOL dislocation had features that would categorize them as challenging cases. Davis et al<sup>40</sup> studied 86 spontaneous late (>3 months) in-the-bag IOL dislocations during 2000 to 2008, reporting a significant increase after 2006. They found that patients with pseudoexfoliation or a history of previous vitreoretinal surgery were important predictors for late IOL dislocation.

Since 1995, ECCE was associated with an increased rate of IOL dislocations, dropped nucleus, and wound dehiscence. This is the first report that complications associated with ECCE have increased and the reasons are unclear. It may be due to surgeon classification bias because ECCE is now mainly used for more complex cataracts or after failed phacoemulsification. Other possible explanations include the smaller number of ECCE procedures during the period (resulting in a large increase in incidence with only small changes in the number of complications); and increasing inexperience with ECCE, as phacoemulsification has become the predominant technique.

Major strengths of our study are its whole-population design spanning 22 years and the large number of cases allowing for increased precision. We used routinely collected administrative data whose main purpose is not for clinical research. Although this may be criticized owing to concerns regarding data accuracy,<sup>41</sup> our careful chart review ensured validation of those complications found. Prior val-



**Figure 2.** Comparison of trends in the incidence of major complications of cataract/lens surgery (per 1000) between 1980 and 2001 for extracapsular cataract extraction (ECCE) technique and phacoemulsification (a-h). The volume of each type of surgery in each year is shown in graphs (g) and (h). Rate ratios (RR) and their 95% confidence intervals (CI) compare the complication rate of phacoemulsification with ECCE adjusted for age, gender, and year of surgery (hazard ratios for retinal detachment, intraocular lens dislocation and pseudophakic corneal edema; incidence rate ratios for wound dehiscence, endophthalmitis and dropped nucleus).

ication of cataract procedure coding errors also enabled us to correct for any miscoding in the denominator cohort.<sup>33</sup>

Because all complications identified in this study were based on either readmission to hospital for surgery or additional surgery being performed during the same admission as the cataract surgery, it is likely we have underestimated the true number of cases. Not all complications require

surgery (e.g., the treating surgeon may decide not to operate or the patient may refuse further surgery). Some complications can also be treated as a minor procedure in the out-patient setting and may be missed (e.g., placing a corneal suture for wound dehiscence or performing laser therapy for retinal tears and small retinal detachments). However, we estimate the number of cases missed owing to such outpa-

Table 4. Incidence of Major Complications (per 1000 procedures) for Extracapsular Cataract Extraction (ECCE) and Phacoemulsification (Phaco) Procedures over Their Respective Transition Periods\*

Procedure	Time Period				IRR <sup>†</sup>		
	Early	Mid	Late	All Years	Early	Mid	Late
ECCE	31.21 (24.55–39.12)	19.34 (16.94–22.00)	20.78 (18.46–23.31)	19.95 (18.70–21.26)	1.00	0.73 (0.56–0.95)	0.79 (0.61–1.03)
Phaco	18.66 (13.14–25.72)	13.05 (11.35–14.93)	9.21 (8.23–10.28)	9.78 (9.03–10.57)	1.00	0.72 (0.50–1.03)	0.52 (0.37–0.74)

Numbers in parentheses are 95% confidence intervals.

\*Extracapsular cataract extraction: Early = 1980–1983, Mid = 1984–1987, Late = 1988–1991; phacoemulsification: Early = 1989–1992, Mid = 1993–1996, Late = 1997–2000.

<sup>†</sup>Age- and gender-adjusted incidence rate ratio (IRR) from a Poisson regression model for having a complication compared to the early period.

tient treatment is likely to be negligible because the standard practice in Western Australia over the study period was to admit patients with these complications for operative management. Furthermore, because we identified those cases serious enough to require further surgery, they are therefore most likely to be clinically significant in terms of their impact on vision and health resources.

The complication profile of cataract surgery in Western Australia improved significantly between 1980 and 2001. Although there was considerable change in operative technique, this alone may not be the sole reason for the reduction in complications; other factors not measured in this study are likely involved. The increase in complications after ECCE, and the increasing trend in IOL dislocation, is concerning and warrants scrutiny.

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Table 1: International Classification of Disease codes used to identify cataract procedures and postoperative complications.

Item	Procedure codes		
	ICD 9 1980 – 1987	ICD 9 CM 1988 – June 1999	ICD 10AM June 1999 onwards
<b>Procedure Type</b>			
Intracapsular	5-144	13.11, 13.19	42698-00, 42702-00, 42702-01
Extracapsular	5-142, 5-145	13.2, 13.3, 13.51, 13.59	42698-01, 42698-04, 42702-02, 42702-03, 42702-08, 42702-09
Phacoemulsification	-	13.41 - 13.43	42698-02, 42698-03, 42702-04, 42702-05, 42702-06, 42702-07
Lens procedure	5-147, 5-149	13.70, 13.71, 13.72, 13.9	42701-00, 42701-01, 42703, 90077-00
Other cataract extraction	5-146	13.64, 13.65, 13.66, 13.69	42734-00, 42719-00, 42719-02, 42698-05, 42788-00, 42722-00, 42731-00, 42702-10, 42702-11, 42731-01, 42716-00
<b>Complication Type</b>			
Retinal detachment	5-152, 5-153, 5-156	14.3 – 14.59, 14.9	42773-00, 42773-01, 42776-00, 42809-01, 90079-00
Intraocular lens dislocation	5-147, 5-149	13.70, 13.72, 13.8	42701-00, 42701-01, 42703-00, 42704-00, 42704-01, 42710-00, 42713-00
Dropped nucleus	5-149, 5-157	13.9, 14.70 – 14.79	42702-10, 42702-11, 42719-01, 42722-01, 42725-00, 42731-01, 42740-05, 9007-00
Pseudophakic corneal edema	5-113, 5-119, 5-125 5-129	10.44, 10.49, 11.53, 11.6, 11.60, 11.61, 11.62, 11.63, 11.64, 11.69	42659-00, 42653-00 42671-00, 90064-00, 42632-00, 42638-00, 42653-01, 42656-00, 90067-00 42551-00, 42551-01, 42551-02, 42554-00,
Wound dehiscence	5-124, 5-126	11.5, 11.51, 11.52, 11.59, 12.83, 12.66	42635-00, 42667-00, 42857-00, 42857-01, 90060-00, 90066-00

ICD = international classification of disease

Table 2: Characteristics of patients with a who experienced a major complication of cataract surgery in Western Australia 1980 to 2001.

	Cataract surgery cohort n (%) <sup>*</sup>	All complications n (%) <sup>*</sup>	Type of Complication					
			Retinal detachment n (%) <sup>*</sup>	IOL dislocation n (%) <sup>*</sup>	Endophth- almitis n (%) <sup>*</sup>	Wound dehiscence n (%) <sup>*</sup>	Corneal edema n (%) <sup>*</sup>	Dropped nucleus n (%) <sup>*</sup>
<b>Total</b>	129,982 (100.0)	2,087 (1.61)	905 (0.70)	361 (0.28)	228 (0.18)	227 (0.17)	207 (0.16)	159 (0.12)
<b>Year<sup>†</sup></b>								
1980 - 1984	10,129 (7.8)	326 (3.22)	155 (1.53)	39 (0.39)	22 (0.22)	26 (0.26)	83 (0.82)	1 (0.01)
1985 - 1989	20,501 (15.8)	440 (2.15)	249 (1.21)	51 (0.25)	33 (0.16)	54 (0.26)	50 (0.24)	3 (0.01)
1990 - 1994	29,319 (22.6)	493 (1.68)	235 (0.80)	72 (0.25)	57 (0.19)	59 (0.20)	42 (0.14)	28 (0.10)
1995 - 2001	70,033 (53.9)	790 (1.13)	242 (0.35)	192 (0.27)	116 (0.17)	88 (0.13)	25 (0.04)	127 (0.18)
<b>Age<sup>‡</sup></b>								
< 50	5,243 (4.0)	215 (4.10)	131 (2.50)	55 (1.05)	6 (0.11)	13 (0.25)	9 (0.17)	1 (0.02)
50-59	8,737 (6.7)	294 (3.36)	176 (2.01)	52 (0.60)	21 (0.24)	21 (0.24)	16 (0.18)	8 (0.09)
60-69	24,554 (18.9)	497 (2.02)	259 (1.05)	74 (0.30)	26 (0.11)	45 (0.18)	61 (0.25)	32 (0.13)
70-79	54,764 (42.1)	669 (1.22)	238 (0.43)	106 (0.19)	93 (0.17)	83 (0.15)	90 (0.16)	59 (0.11)
80 +	36,684 (28.2)	374 (1.02)	77 (0.21)	67 (0.18)	82 (0.22)	65 (0.18)	24 (0.07)	59 (0.16)
<b>Gender</b>								
Male	54,483 (41.9)	1,120 (2.06)	555 (1.02)	199 (0.37)	91 (0.17)	117 (0.21)	76 (0.14)	82 (0.15)
Female	75,499 (58.1)	967 (1.28)	350 (0.46)	162 (0.21)	137 (0.18)	110 (0.15)	131 (0.17)	77 (0.10)
<b>Procedure type</b>								
ECCE	47,868 (36.8)	956 (2.00)	429 (0.90)	151 (0.32)	70 (0.15)	158 (0.33)	101 (0.21)	47 (0.10)
ICCE	5,154 (4.0)	108 (2.10)	57 (1.11)	10 (0.19)	15 (0.29)	10 (0.19)	16 (0.31)	0 (0.00)
Phaco	65,060 (50.1)	638 (0.98)	240 (0.37)	126 (0.19)	111 (0.17)	37 (0.06)	20 (0.03)	104 (0.16)
Other/lens	11,900 (9.2)	385 (3.24)	179 (1.50)	74 (0.62)	32 (0.27)	22 (0.18)	70 (0.59)	8 (0.07)
<b>IOL inserted</b>								
Yes	122,236 (94.0)	1,735 (1.42)	703 (0.58)	361 (0.3)	208 (0.17)	201 (0.16)	151 (0.12)	132 (0.11)
No	7,746 (6.0)	352 (4.54)	202 (2.61)	0 (0.0)	20 (0.26)	26 (0.34)	56 (0.72)	27 (0.35)
<b>Patient locality</b>								
Metropolitan	105,995 (81.5)	1,556 (1.47)	682 (0.64)	274 (0.26)	170 (0.16)	157 (0.15)	166 (0.16)	107 (0.10)
Rural/Remote	23,656 (18.2)	496 (2.10)	201 (0.85)	83 (0.35)	58 (0.25)	67 (0.28)	39 (0.16)	48 (0.20)
Not Classified	331 (0.3)	35 (10.57)	22 (6.65)	4 (1.21)	0 (0.00)	3 (0.91)	2 (0.60)	4 (1.21)
<b>Hospital type<sup>‡</sup></b>								
Public	60,121 (46.3)	943 (1.57)	355 (0.59)	164 (0.27)	95 (0.16)	161 (0.27)	95 (0.16)	73 (0.12)
Private	69,861 (53.7)	1,138 (1.63)	547 (0.78)	196 (0.28)	133 (0.19)	66 (0.09)	110 (0.16)	86 (0.12)
<b>Hospital location<sup>‡</sup></b>								
Metropolitan	117,920 (90.7)	1,806 (1.53)	809 (0.69)	315 (0.27)	194 (0.16)	176 (0.15)	191 (0.16)	121 (0.10)
Rural/Remote	12,062 (9.3)	275 (2.28)	93 (0.77)	45 (0.37)	34 (0.28)	51 (0.42)	14 (0.12)	38 (0.32)

ECCE=extracapsular cataract extraction, ICCE=intracapsular cataract extraction, IOL=intraocular lens

<sup>†</sup> At time of causative cataract procedure. The precise year of cataract operation was unconfirmed in 38 cases (24 retinal detachments, 7 IOL dislocations and 7 pseudophakic bullous keratopathy cases).

<sup>‡</sup> Hospital of surgery was unconfirmed in 6 cases.

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# Risk for Retinal Detachment After Phacoemulsification

## A Whole-Population Study of Cataract Surgery Outcomes

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**Objectives:** To estimate the long-term cumulative incidence of and risk factors for retinal detachment (RD) after phacoemulsification using linked administrative medical data.

**Methods:** We used the Western Australian Data Linkage System to identify patients who underwent phacoemulsification in Western Australia between January 1989 and December 2001. Retinal detachment cases were those patients requiring admission for RD surgery after phacoemulsification that were validated by medical record review. Kaplan-Meier analysis was used to calculate a cumulative incidence. Cox proportional hazards regression modeling was used to determine the association between RD and risk factors, including patient demographics and operative and hospital factors. Some important risk factors, including axial length and Nd:YAG laser capsulotomy, were not examined.


**Results:** We identified 237 RD cases following 65 055 phacoemulsification procedures, with a 10-year cumulative incidence of 0.68% (95% CI, 0.56%-0.83%). Significant risk factors were year of surgery (hazard ratio [HR], 0.43; 95% CI, 0.28-0.66 [1999-2001 compared with 1989-1993] for each 5-year period after 1985), age younger than 60 years (3.76; 2.83-5.00), male sex (1.91; 1.45-2.51), and anterior vitrectomy (27.60; 19.27-39.52). Hospital location, patient rural or remote locality, hospital cataract surgery volume, failed intraocular lens insertion, length of stay, and patient insurance status were not significantly associated with RD.

**Conclusions:** Risk for RD after phacoemulsification has almost halved for each 5-year period since its adoption in the mid 1980s. Younger patient age and male sex at surgery significantly increased risk for RD. Phacoemulsification requiring anterior vitrectomy vastly increased risk for RD.

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**R**ETINAL DETACHMENT (RD) IS one of the most frequent sight-threatening complications of modern cataract surgery and complicates approximately 1% of all cataract operations performed in Western countries.<sup>1-13</sup> Multiple risk factors are implicated, including patient factors (younger age, male sex, and long axial length),<sup>1-4,8,11,14-16</sup> operative factors (surgical technique, vitreous loss, and posterior capsule rupture),<sup>2,6,11,13,17-20</sup> and postoperative factors (Nd:YAG laser posterior capsulotomy).<sup>4,7</sup> Operative technique has been implicated as a significant risk factor for subsequent RD, particularly because the abandonment of intracapsular cataract extraction in favor of extracapsular cataract extraction during the late 1970s resulted in a significant decline in the incidence of pseudophakic RD.<sup>6,7,12,21,22</sup> The subsequent adoption of phacoemulsification cataract surgery as the current

procedure of choice has maintained this reduced risk for RD,<sup>1,2,7,12</sup> despite initial concerns associated with the surgeon learning curve surrounding its adoption.<sup>6</sup>

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Results of population-based investigations suggest that risk for RD after phacoemulsification may remain increased for 10 years after cataract surgery, yet few studies<sup>1,2</sup> followed up patients longer than approximately 5 years. The objectives of our study were to explore changes in the long-term risk for RD after cataract surgery over time since phacoemulsification was first introduced and to identify important population-based risk factors for RD after phacoemulsification in the entire Western Australia (WA) population using validated linked health administrative data. Phacoemulsification was widely

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adopted in WA during the late 1980s and by the mid 1990s had become the procedure of choice in most cataract surgical procedures.<sup>23</sup> The Western Australian Data Linkage System links routinely collected health administrative data sets across the entire WA population, with data sets dating from 1966 onward,<sup>24</sup> and provides the unique ability to study long-term postoperative complications of phacoemulsification on a whole-population level.

## METHODS

We conducted a whole-population retrospective longitudinal study of RD after phacoemulsification. Linked administrative medical data in WA from January 1989 to December 2001 were used.

### STUDY POPULATION

In WA, all cataract and lens-related surgical procedures may only be performed in health facilities licensed with the WA Department of Health. All facilities are required to provide data from all admissions, including patient demographics, comorbidities, primary and secondary diagnoses, and any procedures undertaken or complications arising during the admission. These data, including all admissions from all WA hospitals (public and private), were obtained from the Hospital Morbidity Data Collection, one of the core data sets of the Western Australian Data Linkage System.<sup>24</sup>

We extracted hospital discharge data from the Hospital Morbidity Data Collection for all patients who underwent phacoemulsification cataract surgery between January 1989 to December 2001. Linkage with the State Mortality Register allowed us to account for follow-up loss caused by patient deaths. Phacoemulsification procedures were identified using the *International Classification of Diseases, 9th Revision, Australian Clinical Modification (ICD-9-CM)*<sup>25</sup> codes for procedures 13.41 through 13.43 and the *International Classification of Diseases, 10th Revision, Australian Modification (ICD-10-AM)*<sup>26</sup> codes 42698-02, 42698-03, 42702-04, 42702-05, 42702-06, and 42702-07.

### CASE VALIDATION

All surgically treated RD cases were identified using specific ICD procedure codes associated with RD repair (*ICD-9-CM* codes 14.3 through 14.59 and 14.9 and *ICD-10-AM* codes 42773-00, 42773-01, 42776-00, 42809-01, and 90079-00). Only RD-associated procedures that occurred after the associated phacoemulsification procedure were considered. Potential cases where an RD occurred before the first-ever cataract extraction operation, where eye trauma was involved or where vitreoretinal surgery was performed concurrently were excluded.

As detailed elsewhere,<sup>12</sup> all potential cases were validated by reviewing the patient medical record to confirm that the phacoemulsification procedure and RD occurred in the same eye. Other important operative information, such as procedure type, intraocular lens (IOL) insertion, IOL type, and any other concurrent procedures, were recorded.

### STATISTICAL ANALYSIS

Age was stratified into 10-year age groups (<50, 50-59, 60-69, 70-79, and ≥80 years). Patient locality was defined as metropolitan, rural, or remote on the basis of residential postcode at the time of surgery. Patient insurance status (public or private) was also recorded. The hospital type was classified as public or private, and the hospital location was classified as met-

ropolitan, rural, or remote. We also considered the cataract surgery volume performed at each hospital during the study period, where in the largest hospitals more than 5000 procedures were performed, in the large hospitals 2000 to 5000 procedures were performed, in the medium hospitals 500 to 1999 procedures were performed, and in the small hospitals fewer than 500 procedures were performed. Length of stay was categorized as follows: day case, overnight, or longer than 1 day. Year of surgery was grouped as follows: 1989 to 1993, 1994 to 1998, or 1999 to 2001.

Kaplan-Meier analysis was used to calculate a cumulative incidence of RD (as a percentage of cataract procedures), whereby patients were censored at the time of death or at the end of the follow-up period. Cox proportional hazards regression modeling was used to calculate hazard ratios (HRs) (95% CIs) for each risk factor examined. Using generalized estimating equations, SEs were adjusted for clustering of procedures around individuals. Important risk factors in Cox proportional hazards regression modeling were selected using a backward stepwise variable selection; all covariates were included in an initial model, and the variable with the highest *P* value was sequentially removed until the most parsimonious model remained in which the *P* value for all variables was less than .05. All the statistical analyses were performed using commercially available software (STATA, version 10.0; StataCorp LP).

### ETHICAL CONSIDERATIONS

This study was approved by the human research ethics committees at Curtin University (Perth, Australia), the WA Department of Health, and each of the hospitals involved in the study. Data analysis was performed on deidentified data. Patient information for potential cases was provided only for data validation.

## RESULTS

In total, 65 055 phacoemulsification procedures were performed on 46 258 patients in WA between January 1989 to December 2001, of which 237 (0.4%) were associated with a subsequent admission for RD surgery (**Table**). The crude incidence of RD after phacoemulsification declined by a mean of 19% for each year after 1989 (incidence rate ratio, 0.81; 95% CI, 0.77-0.84) (**Figure 1A**). The median time to RD after phacoemulsification was 11 months (range, 0-8.4 years), with the cumulative incidence increasing almost linearly from 0.47% (95% CI, 0.41%-0.54%) by 5 years after surgery to 0.68% (0.56%-0.83%) by 10 years after surgery (**Figure 1B**). Characteristics of the patients undergoing phacoemulsification procedures and those of the RD cases are summarized in the **Table**.

The mean (SD) age of patients undergoing phacoemulsification procedures was 73.7 (10.3) years (age range, 4-104.4 years). Men were slightly younger than women at the time of surgery (mean difference, 2.4; 95% CI, 2.2-2.6 years; *P* < .001). Most patients were female (58.4%), lived in a metropolitan locality (83.9%), and had private insurance (63.9%).

The mean (SD) age of RD cases was 64.4 (12.9) years (age range, 24-93 years), and 62.4% were male. Younger patient age and male sex were significantly associated with an increased risk for RD identified in the univariate and multivariate Cox proportional hazards regression models (**Figure 2A** and **B**). Compared with those 60 years or older, patients younger than 60 years had almost a

**Table. Characteristics of Patients Undergoing Phacoemulsification Procedures in Western Australia Between January 1989 and December 2001 and Cox Proportional Hazards Regression Analysis of Risk Factors for Retinal Detachment**

Variable	Phacoemulsification Procedure, No. (%) (n=65 055)	Retinal Detachment, No. (%) (n=237)	5-Year Cumulative Incidence, % (95% CI)	Multivariate Model					
				Univariate Model		All Variables		Backward Stepwise Variable Selection	
				HR (95% CI)	P Value	HR (95% CI)	P Value	HR (95% CI)	P Value
Year of surgery									
1989-1993	3974 (6.1)	49 (20.7)	0.96 (0.70-1.32)	1 [Reference]	...	1 [Reference]	...	1 [Reference]	...
1994-1998	28 345 (43.6)	123 (51.9)	0.43 (0.36-0.51)	0.45 (0.31-0.63)	<.001	0.48 (0.32-0.71)	<.001	0.46 (0.32-0.66)	<.001
1999-2001	32 736 (50.3)	65 (27.4)	0.25 (0.19-0.33) <sup>a</sup>	0.41 (0.27-0.62)	<.001	0.45 (0.28-0.73)	.001	0.43 (0.28-0.66)	<.001
Age, y									
≥80	19 112 (29.4)	22 (9.3)	0.11 (0.07-0.18)	1 [Reference]	...	1 [Reference]	...	1 [Reference]	...
70-79	28 800 (44.3)	75 (31.6)	0.33 (0.26-0.42)	2.42 (1.49-3.92)	<.001	2.36 (1.45-3.85)	.59	2.35 (1.45-3.83)	.001
60-69	11 233 (17.3)	64 (27.0)	0.75 (0.57-0.98)	5.06 (3.09-8.28)	<.001	4.28 (2.58-7.10)	.001	4.38 (2.67-7.19)	<.001
50-59	4052 (6.2)	43 (18.1)	1.51 (1.09-2.09)	9.59 (5.69-16.16)	<.001	8.25 (4.79-14.23)	<.001	8.65 (5.10-14.68)	<.001
<50	1858 (2.9)	33 (13.9)	1.99 (1.32-2.99)	13.08 (7.43-23.04)	<.001	9.46 (5.13-17.41)	<.001	10.21 (5.71-18.25)	<.001
Sex									
Female	37 991 (58.4)	89 (37.6)	0.30 (0.24-0.38)	1 [Reference]	...	1 [Reference]	...	1 [Reference]	...
Male	27 064 (41.6)	148 (62.4)	0.70 (0.58-0.83)	2.37 (1.81-3.10)	<.001	1.91 (1.45-2.51)	<.001	1.91 (1.46-2.51)	<.001
Failed intraocular lens insertion									
No	64 623 (99.3)	226 (95.4)	1.70 (0.81-3.54)	1 [Reference]	...	1 [Reference]	...	...	...
Yes	432 (0.7)	11 (4.6)	0.46 (0.40-0.53)	4.86 (2.57-9.20)	<.001	2.28 (1.06-4.93)	.04	...	...
Anterior vitrectomy									
No	64 412 (99.0)	189 (79.7)	0.39 (0.33-0.46)	1 [Reference]	...	1 [Reference]	...	1 [Reference]	...
Yes	643 (1.0)	48 (20.3)	8.31 (6.14-11.20)	26.90 (19.40-37.24)	<.001	27.60 (19.27-39.52)	<.001	28.96 (20.43-41.05)	<.001
Patient locality									
Metropolitan	54 565 (83.9)	183 (77.2)	0.44 (0.37-0.52)	1 [Reference]	...	1 [Reference]	...	...	...
Rural or remote	10 254 (15.8)	52 (21.9)	0.61 (0.45-0.84)	1.52 (1.12-2.08)	.008	1.33 (0.89-1.96)	.16	...	...
Not classified	236 (0.4)	2 (0.8)							
Patient insurance									
Public	23 499 (36.1)	73 (30.8)	0.41 (0.32-0.52)	1 [Reference]	...	1 [Reference]	...	...	...
Private	41 548 (63.9)	163 (68.8)	0.49 (0.40-0.58)	1.14 (0.86-1.51)	.37	0.80 (0.42-1.54)	.51	...	...
Other	8 (0.01)	1 (0.4)							
Hospital type									
Public	23 415 (36.0)	77 (32.5)	0.42 (0.33-0.54)	1 [Reference]	...	1 [Reference]	...	...	...
Private	41 640 (64.0)	160 (67.5)	0.49 (0.41-0.58)	1.13 (0.86-1.48)	.40	1.57 (0.79-3.10)	.20	...	...
Hospital location									
Metropolitan	58 614 (90.1)	214 (90.3)	0.47 (0.40-0.54)	1 [Reference]	...	1 [Reference]	...	...	...
Rural or remote	6419 (9.9)	23 (9.7)	0.46 (0.30-0.71)	1.08 (0.70-1.66)	.73	0.77 (0.40-1.46)	.42	...	...
Not classified	22								
Hospital cataract surgery volume									
>10 000 (n=2)	24 655 (37.9)	114 (48.1)	0.55 (0.45-0.67)	1 [Reference]	...	1 [Reference]	...	...	...
2000-5000 (n=9)	24 739 (38.0)	71 (30.0)	0.37 (0.28-0.47)	0.72 (0.53-0.97)	.03	0.75 (0.49-1.14)	.18	...	...
500-1999 (n=12)	12 513 (19.2)	34 (14.3)	0.37 (0.26-0.54)	0.77 (0.52-1.13)	.19	0.93 (0.60-1.45)	.76	...	...
<500 (n=23)	3148 (4.8)	18 (7.6)	0.72 (0.43-1.21)	1.51 (0.92-2.49)	.11	1.66 (0.88-3.12)	.12	...	...
Length of stay									
Day case	42 690 (65.6)	130 (54.9)	0.44 (0.36-0.54)	1 [Reference]	...	1 [Reference]	...	...	...
Overnight	11 311 (17.4)	46 (19.4)	0.47 (0.34-0.65)	1.13 (0.80-1.59)	.50	0.97 (0.67-1.39)	.86	...	...
>1 d	11 054 (17.0)	61 (25.7)	0.53 (0.41-0.70)	1.18 (0.86-1.62)	.30	0.95 (0.67-1.37)	.80	...	...

Abbreviations: Elipsis, not applicable; HR, hazard ratio.

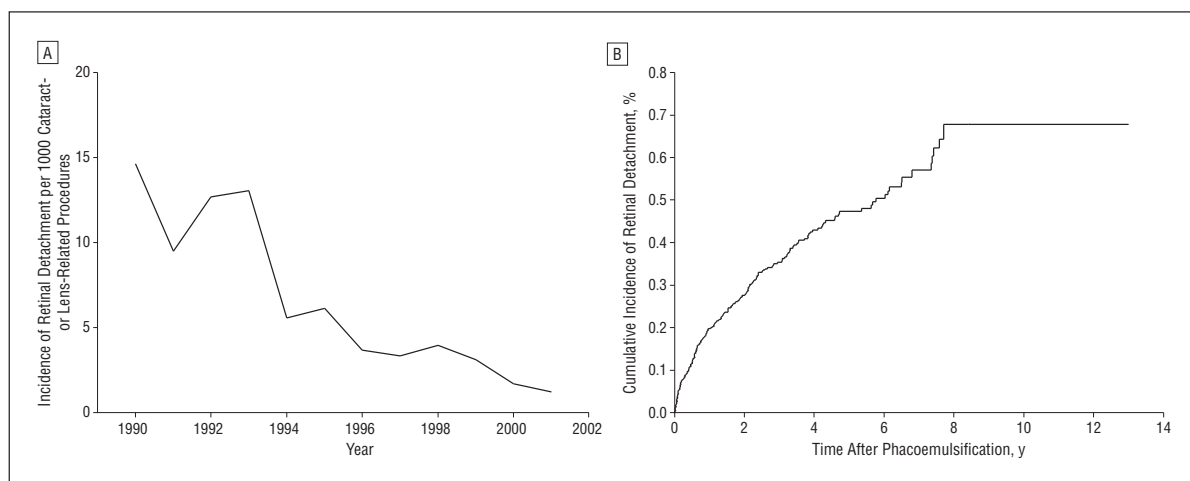
<sup>a</sup>Three-year cumulative incidence.

4-fold increased risk for RD (HR, 3.76; 95% CI, 2.83-5.00;  $P < .001$ ). Compared with women, men were approximately twice as likely to have an RD following their cataract surgery (HR, 1.91; 95% CI, 1.45-2.51;  $P < .001$ ). Among RD cases, age was not significantly different between the sexes ( $P = .21$ ). No other patient factors, including locality and insurance status, were independently associated with risk for RD.

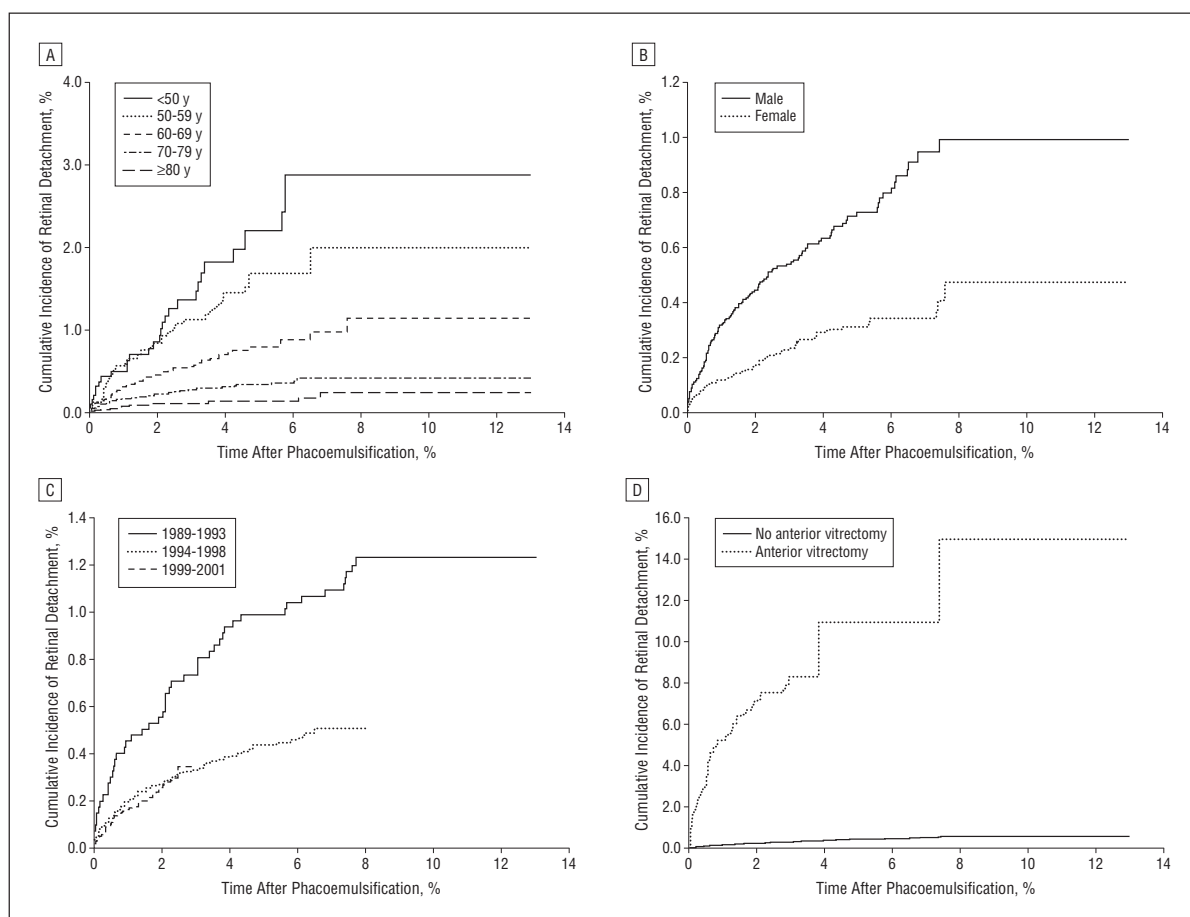
An IOL was not inserted in 432 phacoemulsification procedures (0.7%). In the univariate model, failed IOL insertion was associated with an almost 5-fold increased risk for subsequently having an RD (HR, 4.86;

95% CI, 2.57-9.20;  $P < .001$ ) and with more than twice the risk after adjustment for all other risk factors in the multivariate model (2.28; 1.06-4.93;  $P = .04$ ). However, failed IOL insertion was not significant in the backward stepwise method (excluded at  $P = .06$ ).

Anterior vitrectomy was performed in 643 phacoemulsification procedures (1.0%) and in 48 RD cases (20.3%). The 5-year cumulative incidence of RD after phacoemulsification in which anterior vitrectomy was performed was 8.31% (95% CI, 6.14%-11.20%) and increased to approximately 15% by the end of the follow-up period (Figure 2D). In the backward stepwise variable selection, anterior vi-



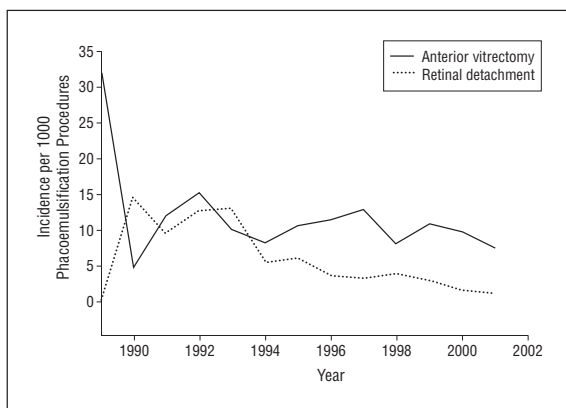
**Figure 1.** Cohort of 65 055 phacoemulsification procedures in Western Australia between January 1989 and December 2001. A, Trends in the crude incidence of retinal detachment. B, Twelve-year cumulative incidence of retinal detachment.



**Figure 2.** Cohort of 65 055 phacoemulsification procedures in Western Australia between January 1989 and December 2001. Comparison of the cumulative incidence of retinal detachment by patient age (A), sex (B), year of surgery (C), and whether anterior vitrectomy was performed during surgery (D) ( $P < .001$  for all by log-rank test).

trectomy was associated with significantly increased risk for RD, which was almost 30 times greater (HR, 28.96; 95% CI, 20.43-41.05;  $P < .001$ ) than operations in which no anterior vitrectomy was performed.

The crude incidence of anterior vitrectomy during cataract surgery declined in the first few years of phacoemulsification adoption in WA and leveled off thereafter at a rate of 10 per 1000 phacoemulsification procedures per-



**Figure 3.** Comparison of the crude incidence of anterior vitrectomy and retinal detachment in a cohort of 65 055 phacoemulsification procedures in Western Australia between January 1989 and December 2001.

formed (**Figure 3**). The crude incidence of RD after cataract surgery showed a similar decline early in the study period and has continued to decline, despite the rate of anterior vitrectomy remaining constant.

Most phacoemulsification procedures (90.1%) were performed in metropolitan hospitals, and 64.0% were in private hospitals. Two hospitals in WA performed more than 10 000 phacoemulsification procedures, accounting for 37.9% of all phacoemulsification procedures performed in the state. Twenty-three hospitals performed fewer than 500 phacoemulsification procedures, which accounted for less than 5% of the total cohort; 14 of these hospitals were in rural or remote areas. A significant proportion (83.0%) of phacoemulsification procedures involved day case or overnight admissions. No hospital variable (location, cataract surgery volume, or public vs private status) was significantly associated with risk for RD in the univariate model or in the multivariate model (Table).

Most phacoemulsification procedures (50.3%) were performed between 1999 and 2001. Approximately a 50% reduction in the incidence of RD was observed for each subsequent year group, from a high of 0.96% from 1989 to 1993 to a low of 0.25% from 1999 to 2001 (Figure 2C). After adjustment for all significant variables in the multivariate model, year of surgery remained significantly associated with risk for RD, such that the HR was 0.43 (95% CI, 0.28-0.66;  $P < .001$ ) by 1999 to 2001 compared with 1989 to 1994.

#### COMMENT

We found that the cumulative incidence of RD after phacoemulsification was almost 0.2% at 1 year (Figure 1B). By comparison, the annual incidence of rhegmatogenous RD in the general population of similar age is reported to be between 22 and 49 cases per 100 000 population.<sup>27-29</sup> Although these measures are not directly comparable, it suggests a substantially increased risk for RD after phacoemulsification above the baseline risk in the general community.

Our findings are comparable with the incidence of RD after phacoemulsification reported elsewhere.<sup>1-11,14,16,19,20</sup> Many of these studies were limited by their smaller sample

sizes,<sup>4,7-11,16,19,20</sup> involved single clinical centers,<sup>4,7-11,16,19,20</sup> or had short follow-up periods ( $<5$  years).<sup>5,10,16,19,20</sup> Our whole-population study captured the entire cohort of patients undergoing phacoemulsification in a well-defined population of 2.2 million people that is representative of the Australian context.<sup>30,31</sup> The WA population has comparatively low out-of-state emigration rates, representing a stable population for longitudinal observation.<sup>31</sup> In addition, a major limitation of previous research using administrative medical data is the inability to confirm that the eye that had the RD was the same eye that underwent cataract surgery.<sup>1,3,5,6</sup> We manually validated all potential RD cases using medical record review and are confident in the details of not only the complication but also the associated surgical procedure.

We found that the cumulative incidence of RD after phacoemulsification continued to increase up to 10 years after surgery. Long-term follow-up data for cataract surgery outcomes on a population-based level are lacking. A population-based study with a long follow-up period ( $>20$  years) by Erie et al<sup>2</sup> reported that the cumulative incidence of RD after extracapsular cataract extraction (including phacoemulsification) was 0.71% at 5 years and 1.23% at 10 years for all the surgical procedures performed between 1980 and 2004 in Olmstead County, Minnesota. Although their cohort also included patients undergoing extracapsular cataract extraction, the authors reported no significant difference in the probability of RD compared with that associated with phacoemulsification. In contrast, risk for RD in our study (cumulative incidence, 0.47% and 0.68% at 5 and 10 years, respectively) was substantially lower than that reported by these authors and may be because of the later time frame of our study.

The incidence of RD after phacoemulsification in WA decreased significantly over time, with a steady decline in the 5-year cumulative incidence from 0.96% from 1989 to 1993, to 0.43% from 1994 to 1998, to 0.25% from 1999 to 2001. This reduction remained significant after adjustment for patient sociodemographic, surgical, and hospital factors. The large fall in incidence from the period representing the adoption of phacoemulsification into routine clinical practice in WA (1989-1993) to plateau thereafter is likely due to surgeon learning curve, although other unmeasured factors, such as improvement in surgical technique and advances in equipment technology, may have contributed to this result.

Less than 1% of phacoemulsification procedures in our cohort involved an anterior vitrectomy, and failed IOL insertion occurred in 0.7%. Although we were unable to confirm every case of posterior capsule rupture that occurred, the data provided for this study allowed us to identify every case of anterior vitrectomy. Our rate of anterior vitrectomy during cataract surgery herein is within the range of other contemporary studies.<sup>32,33</sup> The 5-year cumulative incidence of RD after phacoemulsification in which anterior vitrectomy was performed was 8.31% in our study, with a relative risk approaching 30 times higher than that in surgical procedures in which no anterior vitrectomy was performed.

Many studies<sup>2,6,11,13,17,18,34</sup> demonstrated an increased risk for RD (range, 4.5-19.9 times higher) after surgical procedures documenting posterior capsule rupture with

or without vitreous loss, although a few studies<sup>1,4,35</sup> found no change in risk. Anterior vitrectomy is generally performed only in cataract surgery in which a posterior capsule rupture has occurred with vitreous loss. Similarly, failed IOL insertion would occur in situations of complicated surgery in which capsule support is compromised. Both events could be regarded as a surrogate marker for complicated surgery involving posterior capsule rupture and vitreous loss. These findings highlight the importance of close follow-up monitoring in patients whose cataract surgery has been complicated by posterior capsule rupture because of significant risk for RD that may extend many years after surgery.

We confirm findings in previous large studies<sup>1-3,8,11</sup> of RD after cataract surgery that younger patient age and male sex are significant risk factors for RD. Decreased risk for RD with age is contrary to that in the general community, where risk increases significantly with age.<sup>27-29</sup> In our study, patients younger than 60 years undergoing phacoemulsification were almost 4 times more likely to have an RD compared with those who were 60 years or older. Several theories have been postulated for why younger patients are more likely to experience RD following phacoemulsification. One relates to vitreous changes after cataract surgery. Ripandelli et al<sup>16</sup> found that posterior vitreous detachment occurred following cataract surgery in 75.8% of patients without a history of posterior vitreous detachment or lattice degeneration. Given that 10% to 15% of posterior vitreous detachment occurrences are associated with a retinal tear, older patients may be protected from posterior vitreous detachment because they are more likely to have already had phakic posterior vitreous detachment, which tends to occur in individuals 60 years or older.<sup>15,36</sup> Younger eyes are also more likely to be abnormal in their development of cataract (eg, traumatic cataract), and this may predispose these eyes to pseudophakic RD.

Compared with women, men undergoing phacoemulsification were almost twice as likely to have an RD. The increased risk for RD in men has been reported elsewhere. In a population-based cohort similar to ours, Sheu et al<sup>1</sup> found that men had a 2.43 times higher risk for RD after phacoemulsification than women. Although men in our study were younger on average than women, the observed sex difference remained after adjusting for age. Sex differences in the anatomy of the eye and vitreous have been postulated as potential contributing factors. Men tend to have longer axial length,<sup>37</sup> while women tend toward earlier posterior vitreous detachment.<sup>38</sup> This may confer a protective effect on women for subsequent RD after cataract surgery. Men may also be more likely to experience traumatic injury or to engage in activities where eye trauma is more likely owing to their occupation or lifestyle, placing them at higher risk for pseudophakic RD.

Our study has some limitations. Because all RD cases in the study were identified based on readmission to the hospital for surgery, we likely underestimated the true number of cases in the population. In WA, the standard practice for RD cases during the study period was repair as an inpatient procedure. Procedures that may be performed in an outpatient setting (eg, pneumatic retinopexy) and were not captured were nonstandard and rarely

practiced. Even so, not all patients with RD will undergo surgery (eg, the patient may refuse further surgery), or they may have an RD treated outside of WA and as such would not be captured in the data set. We believe that this number is likely small and that any resultant bias is minimal.

Additional important risk factors for RD after cataract surgery identified in other studies include axial length and the use of Nd:YAG posterior capsulotomy. Axial length of at least 25 mm has been significantly associated with increased relative risk for RD after cataract surgery, approaching 6 times that of eyes with shorter axial length.<sup>14,15</sup> In their population-based study, Ninn-Pedersen and Bauer<sup>4</sup> found that for every 1-mm increase in axial myopia, the associated relative risk for RD was 1.3. Similarly, Nd:YAG laser posterior capsulotomy was associated with increased risk for RD, with a relative risk of 4.9 documented in their study.<sup>4</sup> Unfortunately, it was not possible to analyze these factors in our study because neither characteristic is recorded in the Hospital Morbidity Data Collection.

A strength of our study is its population-based design that includes a widely representative population, identifies most complications, and covers 12 years. Some limitations exist surrounding the use of routinely collected administrative medical data whose main purpose is not for clinical research.<sup>39</sup> The accuracy of such administrative data is dependent on the quality of data processes and systems that create these databases. However, the Western Australian Data Linkage System is a well-established and validated resource that has been used extensively in population-based health research.<sup>30,40</sup> We further added to the quality of data in our study by careful validation of RD via medical record review.

In conclusion, the incidence of pseudophakic RD has declined markedly since the adoption of phacoemulsification cataract surgery in WA. As identified in previous studies, we confirm that younger patient age and male sex are important risk factors for subsequent RD. Complicated operations necessitating anterior vitrectomy carry significantly increased risk for RD. Knowledge about the importance of such risk factors is important for physicians to guide preoperative counseling and postoperative review with patients.

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**Long-term trends and outcomes of anterior**  
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# Long-term trends and outcomes of anterior vitrectomy in Western Australia

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## ABSTRACT.

**Purpose:** To describe trends, risk factors and outcomes of anterior vitrectomy during cataract and intraocular lens (IOL) surgery.

**Methods:** All patients 16 years and older undergoing cataract and IOL surgery in Western Australia (WA) from January 1980 to December 2001 ( $n = 115\,815$ ) were included. Hospital administrative data were used to identify all cataract and IOL procedures and subsequent admissions for retinal detachment, IOL dislocation, endophthalmitis and pseudophakic corneal oedema. Data were validated with chart review and analysed to identify trends and risk factors for anterior vitrectomy and the risk of subsequent complications.

**Results:** In total, 1390 (1.2%) anterior vitrectomies were performed. The rate increased with change in surgical technique. Significant risk factors for anterior vitrectomy were age <50 years (OR 1.31), male sex (OR 1.23), IOL procedure (OR 11.45) and operations in public hospitals (OR 1.99) or rural/remote (OR 1.40) areas. Anterior vitrectomy was strongly associated with increased risk of retinal detachment (RD) (RR 18.5), endophthalmitis (RR 3.6), IOL dislocation (RR 21.1) and pseudophakic corneal oedema (RR 17.3). Retinal detachments and IOL dislocations occur earlier after anterior vitrectomy.

**Conclusion:** Anterior vitrectomy rates have remained stable since the introduction of phacoemulsification. Anterior vitrectomy is a major risk factor for serious complications compared with uncomplicated surgery, particularly RD and IOL dislocation. We identified an increasing trend in anterior vitrectomy being performed during extracapsular and IOL surgery.

**Key words:** administrative data – anterior vitrectomy – cataract surgery – complication – data linkage

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## Introduction

Vitreous loss during cataract surgery remains an inescapable reality of modern cataract surgery, even in the most experienced surgeon's hands. It typically occurs when the integrity of the posterior capsule or lens zonules is

compromised allowing vitreous to prolapse into the anterior chamber, requiring anterior vitrectomy in most cases. Beyond the immediate increase in operation complexity and time, we know that visual outcomes tend to be poorer in the short and long term

(Frost et al. 1995; Ionides et al. 2001; Tan & Karwatowski 2002; Johansson et al. 2009). Post-operative complications such as high intraocular pressure, prolonged inflammation, corneal oedema and cystoid macular oedema are commonly reported (Ionides et al. 2001; Tan & Karwatowski 2002; Johansson et al. 2009), while rare but sight-threatening complications such as retinal detachment and post-operative endophthalmitis are also greatly increased following vitreous loss (Boberg-Ans et al. 2006; Ng et al. 2007; Jakobsson et al. 2009; Clark et al. 2012; Solborg Bjerrum et al. 2013).

Single surgeons or surgical units are limited in their ability to properly study trends, risk factors and outcomes of vitreous loss because it is uncommon. Few studies have reported the rate of significant post-operative complications associated with vitreous loss over the long term (Boberg-Ans et al. 2006; Ng et al. 2007; Jakobsson et al. 2009; Johansson et al. 2009). Even fewer have reported the change in rates of vitreous loss over time (Lundstrom et al. 2011).

We used whole population hospital administrative data to examine the trend in vitreous loss during 115 815 cataract and intraocular lens (IOL) surgery between January 1980 and December 2001 in Western Australia (WA) using anterior vitrectomy as a marker. The study period encompassed two major changes in cataract surgery technique, to extracapsular surgery (ECCE) in the early 1980s and subse-



quently phacoemulsification in the late 1980s/early 1990s. This gave us a unique opportunity to examine the effect of various factors, including surgical technique and surgeon learning curve, on the long-term incidence of anterior vitrectomy and its risk of serious sight-threatening complications including retinal detachment, post-operative endophthalmitis, pseudophakic corneal oedema and IOL dislocation (Clark et al. 2011, 2012).

Our previous work examined trends in the incidence of major sight-threatening complications of cataract surgery (Clark et al. 2011) and identified anterior vitrectomy as one of the major risk factors for retinal detachment after phacoemulsification (Clark et al. 2012). This study extends this work to examine changes in the rates of anterior vitrectomy across all cataract and IOL procedures, the factors associated with necessity for anterior vitrectomy and the subsequent risk of major complications in the longer term.

## Methods

### Study population

This retrospective whole population cohort study used linked administrative data from all public and private hospitals in WA. The state of WA comprises over 2 million people. Although it covers an area larger than Western Europe, the vast majority of people and health services are concentrated in the capital city of Perth. Intraocular surgery in WA can only be performed in health facilities licensed with the WA Department of Health. It is a requirement that these facilities provide data from all admissions, including same-day admissions (public and private) to the WA Department of Health. This data includes patient demographics, co-morbidities, primary and secondary admission diagnoses, and any procedures undertaken or complications arising during the admission. It forms the Hospital Morbidity Data Collection (HMDC), one of the core data sets of the WA Data Linkage System (WADLS; Holman et al. 1999).

We used the WADLS to extract hospital admission data for all patients aged 16 years and over who underwent an ECCE, phacoemulsification cataract extraction or IOL procedure (including secondary IOL insertion and IOL

exchange) from 1980 to 2001. Patients under 16 years were excluded as limited anterior vitrectomy is a routine part of paediatric cataract surgery in WA and would not necessarily indicate a complicated operation. A potential complication was identified by any subsequent admission to hospital for a procedure to treat retinal detachment, IOL dislocation, pseudophakic corneal oedema or endophthalmitis. Procedure data were identified using the time period relevant International Classification of Diseases (ICD) procedure codes. There were 6287 potential complication cases manually validated by reviewing the operative record. All data were linked to the state death register and allowed us to account for loss to follow-up due to death. Further details on this methodology is outlined elsewhere (Clark et al. 2011).

Complications not requiring a procedure (e.g. cystoid macular oedema) or where the procedure does not require hospital admission (e.g. laser posterior capsulotomy for posterior capsule opacification) were not able to be identified in the HMDC and could not be included in the study and adjusted for in the analysis. Similarly, as visual acuity is not recorded in HMDC, nor is it provided in the operative record, visual outcomes were not included.

### Statistical analysis

The age- and sex-standardized rate of anterior vitrectomy was calculated per 100 cataract and IOL procedures. Multivariate logistic regression modelling was used to determine adjusted odds ratio (OR) of risk factors for anterior vitrectomy during cataract and IOL surgery. These included patient age, sex, private insurance status, hospital type (public versus private), hospital cataract and IOL surgery volume, and year of surgery. The risk of a complication following anterior vitrectomy was calculated using logistic regression models for endophthalmitis and IOL dislocation, and Cox-proportional hazards regression models for retinal detachment and pseudophakic bullous keratopathy (to account for their longer lead time and differing follow-up periods; Clark et al. 2011). Both models were adjusted for age, sex, year of surgery and procedure type. Standard errors were adjusted for clustering

of procedures on individuals using generalized estimating equations.

Multivariate linear regression models adjusting for age and sex were used to compare the time to complication for retinal detachment and IOL dislocation for the anterior vitrectomy and non-anterior vitrectomy cohorts. Kaplan–Meier failure curves were produced comparing survival time between groups.

An attributable risk associated with anterior vitrectomy for each complication was calculated as the difference in complication incidence in the anterior vitrectomy cohort ( $I^{\text{exp}}$ ) compared with the uncomplicated cataract surgery cohort ( $I^{\text{unexp}}$ ), that is,  $AR = I^{\text{exp}} - I^{\text{unexp}}$ . Number needed to harm was calculated as  $1/AR$  and represents the number of anterior vitrectomies required to result in an additional complication. All analysis was performed using STATA 11.0 (StataCorp, College Station, TX, USA).

### Ethics

This study was approved by the human research ethics committees at Curtin University, The University of Western Australia, The WA Department of Health, and each of the hospitals involved in the study. All data analysis was carried out on de-identified data. Patient information was provided only for potential cases for the purposes of data validation.

## Results

There were 115 815 patients aged 16 years and over who underwent cataract or IOL surgery in WA between January 1980 and December 2001 (Table 1). The majority were women (58.1%) and older than 70 years (71.3%). Most procedures were phacoemulsification (56.1%) in private facilities (55.2%) between 1995 and 2001 (58.6%). IOL procedures consisted of secondary IOL insertion ( $n = 1755$ ; 63.2%), IOL exchange ( $n = 283$ ; 9.2%), IOL repositioning ( $n = 29$ ; 1%) and unspecified IOL procedures ( $n = 817$ ; 26.6%).

A total of 1390 anterior vitrectomies were performed during cataract and IOL surgery, accounting for 1.2% of all procedures. The age- and sex-standardized rate of anterior vitrectomy peaked at 4.8% [95% confidence inter-

**Table 1.** Logistic regression model of risk factors for anterior vitrectomy during cataract and intraocular lens (IOL) surgery in Western Australia (1980–2001).

Variable	Surgery cohort (n = 115 815)	Anterior vitrectomy (n = 1390)	Odds ratio (95% CI)	p-value*
Age, n (%)				
80+	33 248 (28.7)	386 (1.2)	1.00	
70–79	49 332 (42.6)	500 (1.0)	0.87 (0.76–0.99)	0.039
60–69	21 635 (18.7)	291 (1.3)	1.11 (0.95–1.3)	0.206
50–59	7596 (6.6)	102 (1.3)	1.04 (0.83–1.3)	0.726
< 50	4004 (3.5)	111 (2.8)	1.31 (1.03–1.7)	0.029
Sex, n (%)				
Female	67 300 (58.1)	710 (1.0)	1.00	
Male	48 515 (41.9)	680 (1.4)	1.23 (1.11–1.4)	<0.001
Operation type, n (%)				
ECCE	47 718 (41.2)	449 (0.9)	1.00	
Phacoemulsification	65 025 (56.1)	641 (1.0)	0.85 (0.73–0.99)	0.042
IOL	3072 (2.7)	300 (9.8)	11.45 (9.7–13.6)	<0.001
Hospital volume, n (%)				
>10 000	36 353 (31.4)	285 (0.8)	1.00	
2000–10 000	62 911 (54.3)	922 (1.5)	1.14 (0.96–1.4)	0.144
<2000	16 551 (14.3)	183 (1.1)	0.80 (0.63–1.0)	0.06
Hospital type, n (%)				
Private	63 921 (55.2)	514 (0.8)	1.00	
Public	51 894 (44.8)	876 (1.7)	1.99 (1.7–2.3)	<0.001
Metro	103 836 (89.7)	1183 (1.1)	1.00	
Rural/remote	11 979 (10.3)	207 (1.7)	1.40 (1.2–1.7)	<0.001
Year, n (%)				
1980–1984	5226 (4.5)	93 (1.8)	1.00	
1985–1989	17 947 (15.5)	162 (0.9)	0.72 (0.55–0.94)	0.017
1990–1994	24 783 (21.4)	270 (1.1)	1.09 (0.85–1.4)	0.496
1995–2001	67 859 (58.6)	865 (1.3)	1.62 (1.3–2.1)	<0.001

\* From a logistic regression model adjusting for all other variables in Table 1.

val (CI) 1.18–8.41] early in the study period before declining to a steady rate of approximately 1% by 1985. This increased slightly towards 1.5% following the introduction of phacoemulsification in the early 1990s before plateauing again at 1% by 1994. For ECCE procedures, there was a ‘U’-shaped curve with a steady increase in the rate of anterior vitrectomy after a low of 0.4% (95% CI 0.18–0.58) in 1990 to a high of 4.3% (95% CI 2.2–6.5%) by 2001 (Fig. 1). Similarly, the rate of anterior vitrectomy for IOL procedures increased 5% per year over the study period (IRR 1.05, 95% CI 1.03–1.07; Fig. 2).

Risk factors for anterior vitrectomy are shown in Table 1. Greater risk of vitreous loss and anterior vitrectomy was seen in those younger than 50 years (OR 1.33, 95% CI 1.03–1.7); men (OR 1.23, 95% CI 1.1–1.4); IOL surgery (OR 11.45, 95% CI 9.7–13.6); and surgery in public (OR 1.99, 95% CI 1.7–2.3) or rural/remote (OR 1.40, 95% CI 1.2–1.7) hospitals. Phacoemulsification had 15% less risk of requiring

anterior vitrectomy than ECCE (OR 0.85, 95% CI 0.73–0.99). Hospital surgical volume was not significantly associated with rate of anterior vitrectomy. There was no significant difference in the risk of anterior vitrectomy between the different types of IOL procedures (Pearson chi squared 11.46,  $p = 0.09$ ).

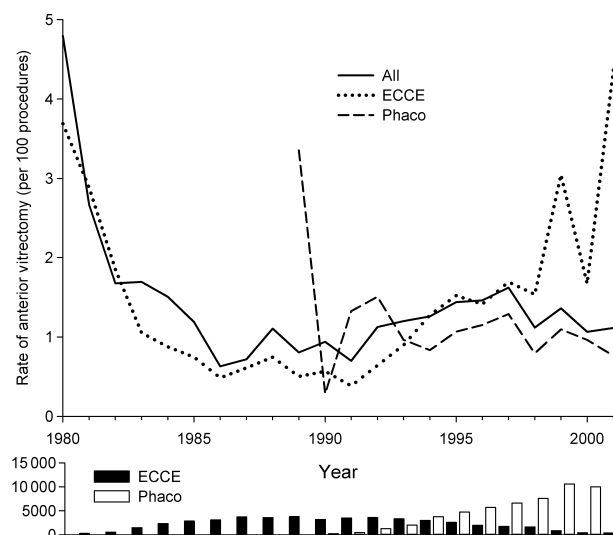
There were 236 complications of interest following 212 cataract operations requiring anterior vitrectomy. This accounted for 15% of the anterior vitrectomy cohort compared with 1.1% of the uncomplicated cataract surgery cohort (Table 2). Retinal detachment (8.7%) and IOL dislocation (4.5%) were the most common complications after anterior vitrectomy, while post-operative endophthalmitis was the least common (0.6%). In the multivariate model controlling for age, sex, surgery type and year of surgery, all complications were significantly increased after anterior vitrectomy (Table 2). The number needed to harm for anterior vitrectomy was particularly low for retinal detachment (12) and IOL dislocation (21).

There was a significant difference in the time to complication between the anterior vitrectomy cohort and the uncomplicated surgery cohort for retinal detachments and IOL dislocations. Retinal detachments occurred 1.6 years earlier (95% CI 1.01–2.18,  $p < 0.001$ ) while IOL dislocations occurred 11 months earlier (95% CI 0.07–1.75,  $p = 0.034$ ) after controlling for age and sex. Nearly half the number of retinal detachments occurred within the first year after complicated surgery, while it took over 2 years before a similar proportion occurred after uncomplicated surgery (Fig. 3A). Most IOL dislocations occurred within the first few months after surgery for both complicated and uncomplicated operations. Where anterior vitrectomy was performed, 75% of IOL dislocations occurred within 6 months, compared with <50% within 6 months for procedures where anterior vitrectomy was not performed (Fig. 3B).

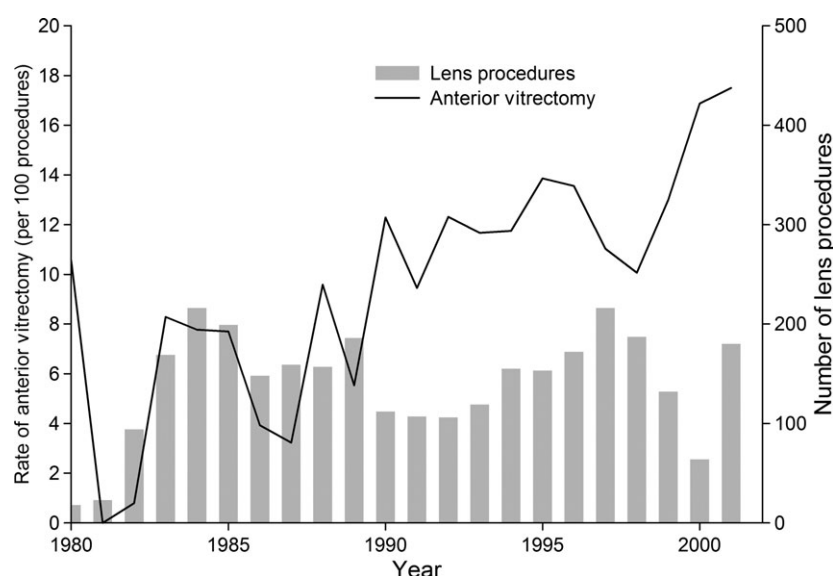
## Discussion

The overall incidence of anterior vitrectomy in our study was 1.2%, which compares favourably to other studies where the incidence ranged from 1.1% to 5.4% (Ionides et al. 2001; Chan et al. 2003; Nagashima 2004; Bhagat et al. 2007; Narendran et al. 2009; Lundstrom et al. 2011). We found two main peaks in the rate of anterior vitrectomy that coincided with significant changes in surgical technique, illustrating the impact of surgeon learning curve on intraoperative complications. The first was during the transition from intracapsular to ECCE in the 1980s and a second broader peak occurred in the first half of the 1990s as phacoemulsification was introduced. The incidence has since stabilized at around 1% as phacoemulsification took over as the predominant procedure (Fig. 1).

The reason for the increasing trend in vitreous loss during ECCE in the latter part of the study period is likely multifactorial. As phacoemulsification was adopted, the complexity of patients undergoing ECCE would have increased as the technique would only be used where phacoemulsification was not felt possible (e.g. extremely dense nucleus or significant zonular instability). As surgeons became more comfortable with phacoemulsification, the



**Fig. 1.** Age- and sex-standardized rate of anterior vitrectomy during extracapsular (ECCE) and phacoemulsification (phaco) cataract surgery in Western Australia (1980–2001).



**Fig. 2.** Age- and sex-standardized rate of anterior vitrectomy during intraocular lens (IOL) surgery in Western Australia (1980–2001).

complexity of cases reserved for ECCE would likely further increase over the course of the study period. Increased

complexity of cases is well reported to be associated with higher risk of capsule complications and subsequent vitreous

loss (Narendran et al. 2009). There are also likely to be instances where ECCE was performed only after attempted phacoemulsification resulted in vitreous loss requiring conversion to ECCE and anterior vitrectomy. Finally, as surgeons are doing less ECCE, they are likely to have become less skilled at performing the procedure.

The rate of anterior vitrectomy during IOL surgeries increased linearly and doubled over the 21 years of the study (Fig. 2). To our knowledge, no other studies have reported the trend in anterior vitrectomy during IOL surgery with which to compare these findings. The reason for this increase is not immediately apparent. It is well reported that IOL exchange procedures have high rates of anterior vitrectomy between 21% and 72% (Marques et al. 2007; Leysen et al. 2009), which is potentially doubled if Nd/YAG laser capsulotomy for posterior capsule opacification was performed prior to surgery (Leysen et al. 2009). The evolution in IOL design over the study period to allow in the bag placement would conceivably increase the risk of capsule complications during IOL removal. Additionally, the widespread adoption of acrylic lenses designed to increase adherence to the capsule and reduce posterior capsule opacification would increase the risk of capsule rupture during attempted removal over less adherent PMMA and silicone lenses used earlier in the study period (Cooke et al. 2006).

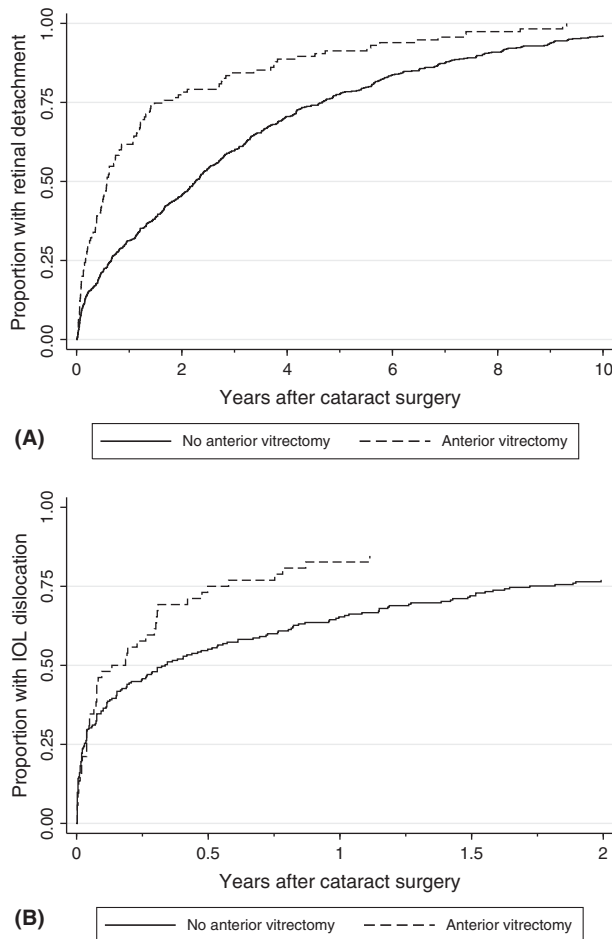
The significance of age as a risk factor for anterior vitrectomy is inconsistent across other studies. Narendran et al. (2009) in their electronic cataract data set study of 55 567 cataract operations in the UK found those older than 80 years had an OR of 1.58 (95% CI 1.20–2.08) compared with those <60 years old. Others have found either no significant difference or only a small trend with increased age (Art-

**Table 2.** Risk of serious complication following cataract and IOL-related surgery where anterior vitrectomy was performed.

Complication	n	Anterior vitrectomies (%)	RR (95% CI)*	p-value	AR (%)	NNH
IOL dislocation	290	62 (4.5)	21.1 (15.1–29.5)	<0.001	4.26	23
Post-operative endophthalmitis	187	8 (0.58)	3.6 (1.7–7.6)	0.001	0.42	239
Retinal detachment	688	121 (8.7)	18.5 (15.0–22.8)	<0.001	8.21	12
Pseudophakic corneal oedema	140	26 (1.9)	17.3 (10.8–27.9)	<0.001	1.77	56

\* Relative risk – hazard ratio for retinal detachment and pseudophakic corneal oedema and odds ratios for IOL dislocation and post-operative endophthalmitis. Controlled for patient age and sex, year, type of cataract surgery and location of surgery.

AR = attributable risk, NNH = number needed to harm, IOL = intraocular lens.



**Fig. 3.** A comparison of the time to retinal detachment (A) and intraocular lens (IOL) dislocation (B) for cataract surgery where anterior vitrectomy was and was not performed in Western Australia (1980–2001; logrank  $p < 0.05$  for both).

zen et al. 2009; Lundstrom et al. 2011). We found a bimodal risk where those aged  $<50$  years and  $80+$  years had higher rates compared with the 60–79 year group. This was significant in the  $<50$  year group and may be due younger eyes being more likely to be abnormal (e.g. traumatic cataract and uveitic cataracts), which have an increased risk of vitreous loss. The older group possibly have denser cataracts and potentially weaker zonules, whilst the 60–79 year group were the ones most likely to have straightforward cataracts.

The effect of gender on risk for anterior vitrectomy is similarly inconsistent across studies. We found similar results to Narendran et al. (2009) where men had 23% greater odds of anterior vitrectomy. The Swedish Capsule Rupture study group reported a higher but not statistically significant increase in posterior capsule rupture rates for men. This greater risk may be because men are more likely to suffer

ocular trauma and present later for cataract surgery than women.

Patients operated in public hospitals had nearly twice the risk of needing an anterior vitrectomy compared with those having surgery in private facilities. There are socioeconomic and health differences between patients who attend public versus private institutions. Public patients in WA have greater comorbidity and reduced access to healthcare services (Semmens et al. 2003; Ng et al. 2005, 2006). They tend to present late with more severe cataract, contributing to a different surgical case mix in the public setting with inherently greater risk of complications. Additionally, trainee surgeons operate exclusively in the public hospital setting and are known to have increased rates of vitreous loss during the surgical learning curve (Tan & Karwatowski 2002; Bhagat et al. 2007; Johnston et al. 2010; Fong et al. 2012) with a reported odds ratio compared with consultant surgeons of 3–4

times (Artzen et al. 2009; Narendran et al. 2009).

Those having cataract and IOL surgery in rural/remote hospitals were more likely to undergo anterior vitrectomy than their metropolitan counterparts. WA covers 2.5 million  $\text{km}^2$  with a rural/remote population spread across the vast state contributing to reduced access and later presentations for surgery leading to increased complexity (Ng et al. 2006). Smaller rural community hospitals also tend to be equipped with older surgical equipment that further increases the difficulty of already challenging surgery.

All of the major sight-threatening complications we examined were more likely after surgery where anterior vitrectomy was required. This reinforces the importance of appropriate patient counselling following complicated surgery regarding the potential for long-term complications, particularly retinal detachment.

Our study has several strengths. The whole population design captured the entire WA cataract surgery population over a 20-year period providing excellent opportunity to study complications such as retinal detachment, IOL dislocations and pseudophakic corneal oedema, which may occur many years after surgery (Boberg-Ans et al. 2006; Clark et al. 2011). The WA population is ideal for population-based research as its isolation with little outward migration creates a stable, captured cohort with little loss to follow-up. Despite its isolation, WA remains highly representative of the wider Australian population in key demographic indices, increasing external validity to the wider Australian population (Clark et al. 2010).

Limitations of our study relate to the use of routinely collected hospital administrative data that are not primarily used for clinical research. The accuracy of the data is dependent on the surgeon accurately recording information in the operation report and clinical coders accurately coding this information into the administrative database. We are confident in the quality of data in the WADLS, which has been thoroughly validated over two decades of population-based health research in WA (Holman et al. 2008). However, the true rate of vitreous loss may be under-reported due to omissions from the operating report. Vitre-



ous complications are often stigmatized among surgeons, and self-reported rates may be lower than reality. Additionally, cases of vitreous loss where anterior vitrectomy was not performed for whatever reason will also not be identified. Important sight-threatening complications associated with vitreous loss and managed on an outpatient basis such as cystoid macular oedema and ocular hypertension were not recorded in the hospital administrative data and so could not be included. Similarly, outpatient procedures such as Nd:YAG capsulotomy were not recorded and thus could not be adjusted for in the analysis.

In conclusion, we found the trend for anterior vitrectomy during phacoemulsification was a decreasing one, while ECCE and IOL surgeries have shown an increasing trend likely due to changes in surgical complexity and surgeon experience. While overall rates of anterior vitrectomy during cataract surgery remain low, it is strongly associated with serious post-operative complications. Particular attention should be paid to risk of retinal detachment and IOL dislocation in the long term.

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### **3.5. Conference Presentations**

**Free paper:** Clark A, Morlet N, Ng JQ, Preen DB, Semmens JB. *Significant risk factors for retinal detachment after phacoemulsification: A population-based data linkage study of cataract surgery outcomes in Western Australia over 22 years*

Antony Clark • Nicol Meekle • Jonathan O'Ne • James Semmens

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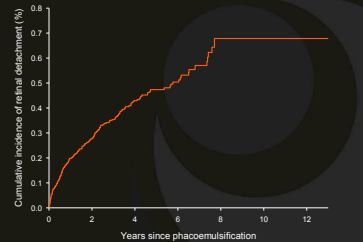
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**237 retinal detachments from 65,056 phacoemulsification surgeries (0.37%) in WA**



## Patient factors

- \*P<0.001

**Cumulative incidence of retinal detachment (%)**

**OR (95%CI)**

Age Group	OR (95%CI)
< 50 yrs	10.2 (5.7-18.2)
50 - 59 yrs	8.6 (5.1-14.7)
60 - 69 yrs	4.38 (2.7-7.2)
70 - 79 yrs	2.35 (1.4-3.8)
> 80 yrs	1.00

**Years since phacoemulsification**

**Cumulative incidence of retinal detachment (%)**

**Male** (solid line)  
**Female** (dotted line)

**OR (95%CI)**  
**1.9 (1.5-2.5)**

**1.00**

**0.0 0.2 0.4 0.6 0.8 1.0 1.2**

**0 2 4 6 8 10 12**

**Years since phacoemulsification**

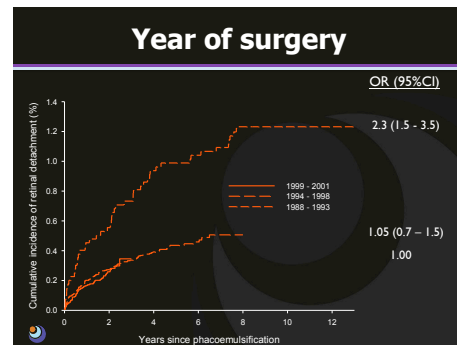
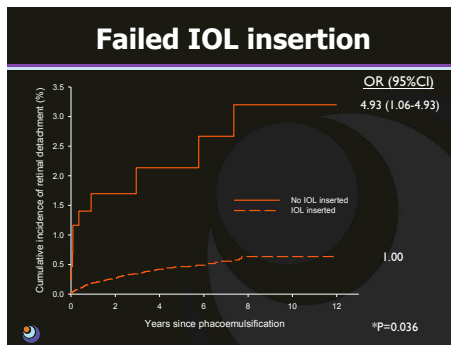
Cumulative incidence of retinal detachment (%)

Years since phacoemulsification

— No anterior vitrectomy  
- - Anterior vitrectomy

OR (95%CI)  
29.0 (20.4 - 41.0)

1.00



- ### Conclusions
- Long-term follow-up essential
  - Non-surgical risk factors are important
  - Potential for risk stratification
  - Unmeasured factors



**Free paper:** Clark A, Morlet N, Ng JQ, Preen DB, Semmens JB. *The risk profile of major sight-threatening complications of cataract surgery: a population-based data linkage study of cataract surgery outcomes in Western Australia over 22 years*


### The risk profile of major sight-threatening complications of cataract surgery:

A whole-population data linkage study of cataract surgery outcomes in Western Australia over 22 years

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 Centre for Population Health Research, Curtin Health Innovation Research Institute, Curtin University of Technology, Perth, Western Australia

#### The WA Data Linkage System

- >20million records (3.9 million chains) across 8 core datasets (~1970-present)
- WA population geographically isolated, stable and representative
- Validated resource ideal for population-based research



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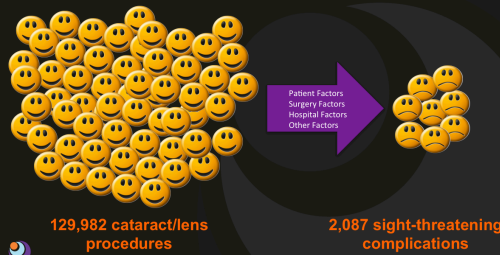
## Methods

- Linked health administrative datasets identified:
  - All cataract procedures (1980-2001)
  - Subsequent admissions for complication requiring surgery
- Validation by chart review :
  - Confirm complication
  - Obtain operative details
- OR from multivariate logistic regression



## Study design

### Retrospective whole-population cohort study



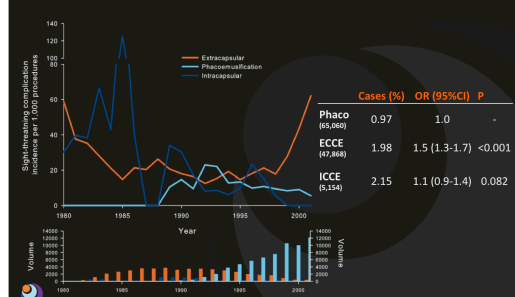
## Risk factors explored

- Patient factors
  - Age
  - Sex
  - Locality of residence
  - Health insurance
- Surgical factors
  - Procedure type
  - IOL insertion
  - Other procedures
- Hospital factors
  - Type
  - Surgical volume
  - Length of stay
  - Location
- Others
  - Year of surgery

## Significant findings

Patient Factors	OR	(95% CI)	P
Age			
80 +	1.0	-	-
60 – 79	1.4	(1.2 – 1.5)	<0.001
< 60	2.6	(2.2 – 3.0)	<0.001
Gender			
Female	1.0	-	-
Male	1.4	(1.2 – 1.5)	<0.001
Insurance status			
Private	1.0	-	-
Public	1.3	(1.0 – 1.5)	0.02
Surgical Factors			
Anterior vitrectomy	21.1	(18.0 – 24.6)	<0.001

## Procedure type



## Significant findings

Hospital factors	OR	(95% CI)	P
Hospital Type			
Public	1.0	-	-
Private	1.6	(1.3 – 2.0)	<0.001
Hospital Location			
Metropolitan	1.0	-	-
Rural/Remote	1.3	(1.1 – 1.6)	0.003
Other factors			
Year of surgery	0.95	(0.94 – 0.97)	<0.001

## Conclusions

- Cataract surgery is safety has improved
- Non-surgical risk factors are important
- Importance of health systems
- Potential for risk stratification
- Unmeasured factors

**Poster: Clark A, Morlet N, Ng JQ, Preen DB, Semmens JB. Trends and outcomes of anterior vitrectomy during cataract surgery: a population-based data linkage study of cataract surgery outcomes in WA over 22yrs.**

# Trends and outcomes of anterior vitrectomy during cataract surgery

A whole-population study of cataract surgery outcomes in Western Australia over 22 years.

Antony Clark • Nigel Morlet • Jonathon Q Ng • James Semmens  
Centre for Population Health Research, Curtin Health Innovation Research Institute, Curtin University of Technology

## Introduction

We examined the change in incidence of anterior vitrectomy in cataract surgery over time for all cataract operations performed in Western Australia (WA) between 1980 and 2001. We also examined the association of anterior vitrectomy with the risk of a major sight-threatening complication of cataract surgery.

## Methods

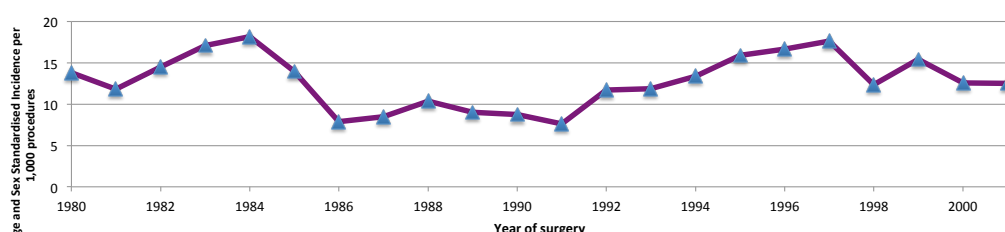
We used the WA Data Linkage System, which includes all State hospital and death records, to identify patients who underwent cataract surgery in all public and private hospitals in WA for 1980-2001. All procedures where an anterior vitrectomy was performed during cataract surgery were identified using clinical procedure codes (ICD9, ICD9CM and ICD10). Potential sight-threatening complications were identified from those patients who underwent eye surgery following their cataract surgery. All cases were validated by cross-referencing with the hospital medical record.

**Table 1: Patient and surgical characteristics of cataract surgery where anterior vitrectomy was performed.**

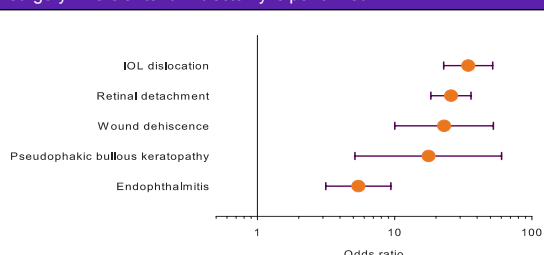
Characteristic	N (%)	OR (95% CI)*
<b>Age (years)</b>		
80 +	417 (1.1)	1.0
70 - 79	545 (1.0)	0.87 (0.77-0.99)
60 - 69	325 (1.3)	1.10 (0.95-1.3)
50 - 59	121 (1.4)	1.05 (0.85-1.3)
< 50	285 (5.4)	3.03 (2.57-3.57)
<b>Gender</b>		
Female	843 (1.1)	1.0
Male	861 (1.6)	1.25 (1.13-1.38)
<b>Cataract surgery type</b>		
Phacoemulsification	643 (0.99)	1.0
Extracapsular	479 (1.0)	1.41 (1.22-1.62)
Intracapsular	127 (2.5)	3.31 (2.69-4.08)
Lens procedure	310 (9.9)	10.9 (9.28-12.81)
'other' cataract	145 (1.7)	2.44 (1.98-3.00)

\*odds ratio from a logistic regression model adjusted for all other variables in the table and year of surgery.

**Figure 1: Trend in anterior vitrectomy during cataract surgery in WA 1980-2001**



**Figure 2: Risk of sight-threatening complications after cataract surgery where anterior vitrectomy is performed.**



## Results

1,704(1.3%) anterior vitrectomies were performed during 129,982 cataract surgeries in WA 1980-2001 (Table 1). The incidence of anterior vitrectomy demonstrated two clear peaks in the early-1980s and early-1990s coinciding with the transition in surgical technique (Figure 1). 360 (21%) cataract surgeries involving anterior vitrectomy resulted in a sight-threatening complication. This included 50 (3.7%) retinal detachments, 9 (0.7%) pseudophakic bullous keratopathies, 35 (2.6%) IOL dislocations, 5 (0.4%) wound dehiscences, 55 (4.1%) dropped nuclei and 6 (0.4%) endophthalmitis cases (Figure 2).

## Conclusion & Discussion

The peaks in anterior vitrectomy coincide with major changes in surgical technique and may reflect a surgeon's learning curve during the transition from intracapsular to extracapsular extraction and then to phacoemulsification. As expected, patients with anterior vitrectomy had a significantly higher higher risk of complication.

## Funding

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**Acknowledgments**  
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**Disclosure**  
The authors have no financial interest in the material presented in this poster.

# Trends in sight-threatening complications of cataract surgery in Western Australia 1980-2001

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ROYAL PERTH HOSPITAL, WESTERN AUSTRALIA

## Background & Aims

Our aim was to extend our previous published work on postoperative endophthalmitis to describe the trends in other major sight threatening complications of cataract surgery in Western Australia (WA) in a whole-population cohort who have undergone cataract surgery since 1980. Complications of interest were:

- retinal detachment
- pseudophakic bullous keratopathy
- intraocular lens dislocation
- dropped nucleus
- wound dehiscence
- postoperative endophthalmitis

## Methods

The Western Australian Data Linkage System (WADLS) was used to identify and link all 129,982 patients undergoing cataract and lens-related surgery in Western Australia between 1980 and 2001. Hospital procedure codes specific to each complication of interest were used to identify patients who had a potential sight threatening complication following their cataract surgery. Validation of 5,631 potential cases was undertaken through medical chart review.

## Conclusions

The overall trends in the major sight-threatening complications of cataract surgery in WA has declined significantly since 1980, particularly for retinal detachment and pseudophakic bullous keratopathy. The introduction of phacoemulsification cataract surgery has had a favourable impact on complication rates since it's introduction in the late 1980s. The recent increase in complications associated with extracapsular cataract extraction is of concern and requires further investigation.

## Funding

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This study was funded by the National Health and Medical Research Council of Australia, projects 110250 and 303114.

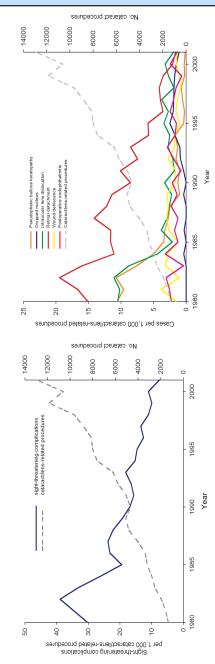
## Acknowledgments

**Acknowledgments**  
We thank the Data Linkage WA of the Western Australian Department of Health.

## Disclosure

**Disclosure**  
The authors have not financial interest in the material presented in this poster.

# Trends in major sight-threatening complications of cataract surgery 1980-2001



### Trend in sight-threatening complications of cataract surgery by procedure type

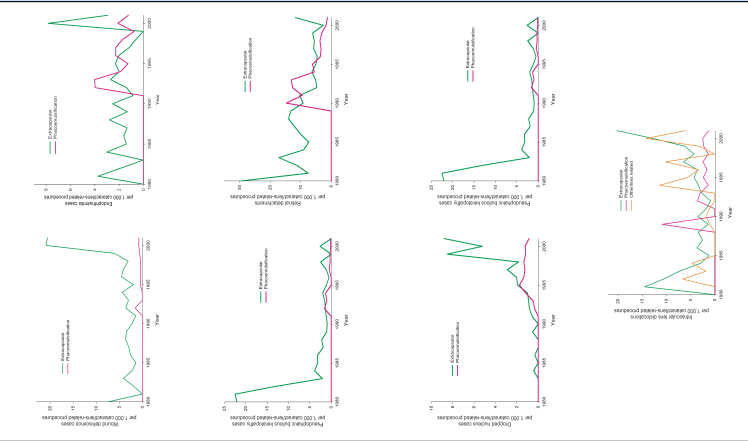
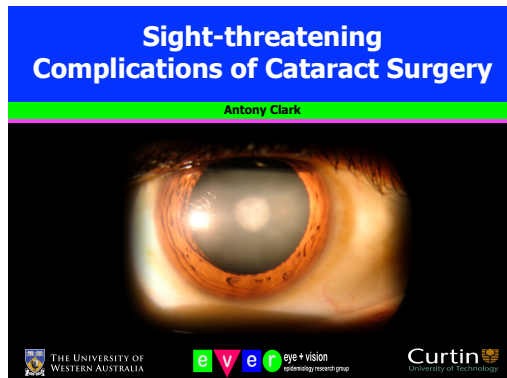


Table 1. Number of complications by year and cataract procedure type

	1980-1984	1985-1989	1990-1994	1995-2001	Total
<b>Intraocular procedures</b>					
Retinal detachment	39	8	9	2	58
Pseudophakic bulbus keratopathy	12	0	3	0	15
Dropped nucleus	0	0	0	0	0
Intraocular lens dislocation	3	2	1	4	10
Wound dehiscence	0	1	4	10	15
Postoperative endophthalmitis	11	1	1	0	13
<b>Extracapsular procedures</b>					
Retinal detachment	58	197	218	51	424
Pseudophakic bulbus keratopathy	28	39	23	11	101
Dropped nucleus	1	3	11	29	44
Intraocular lens dislocation	18	40	39	53	150
Wound dehiscence	13	49	48	46	156
Postoperative endophthalmitis	9	29	30	15	83
<b>Phacemulsification procedures</b>					
Retinal detachment	-	3	70	164	237
Pseudophakic bulbus keratopathy	-	0	9	11	20
Dropped nucleus	-	0	14	87	101
Intraocular lens dislocation	-	1	15	110	126
Wound dehiscence	-	0	2	33	35
Postoperative endophthalmitis	-	0	22	96	118
<b>Other/lens-related procedures</b>					
Retinal detachment	1	7	4	10	22
Pseudophakic bulbus keratopathy	10	5	4	2	21
Dropped nucleus	0	0	0	1	1
Intraocular lens dislocation	6	1	5	11	23
Wound dehiscence	0	1	2	5	8
Postoperative endophthalmitis	3	3	4	4	14

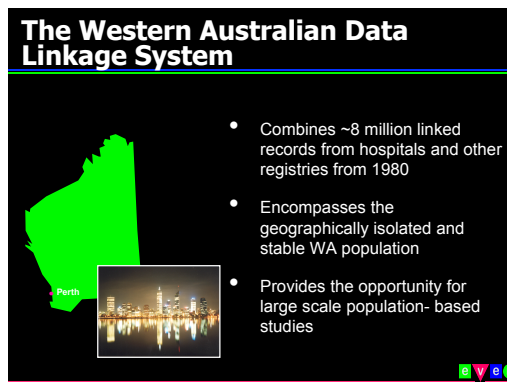
# 39<sup>th</sup> Annual Royal Australian and New Zealand College of Ophthalmologists Annual Scientific Conference. Perth, Australia. November 2007.

**Free paper: Clark A, Ng JQ, Morlet N, Semmens JB. *Complications After Cataract Surgery in Western Australia 1980 to 2000.***



## Study Aim

- To develop a validated dataset of the major sight-threatening complications after cataract surgery 1980-2001
  - Retinal detachment
  - Pseudophakic bullous keratopathy
  - Dropped nucleus
  - Wound dehiscence
  - IOL dislocation
- To describe their trends in incidence over time



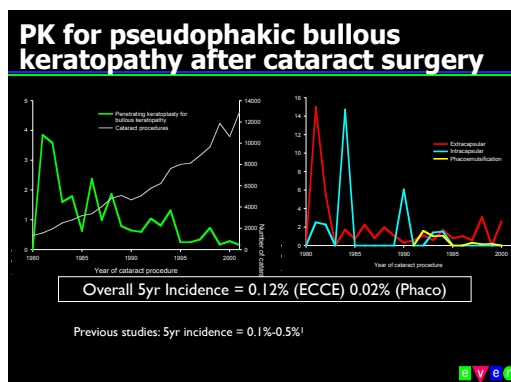
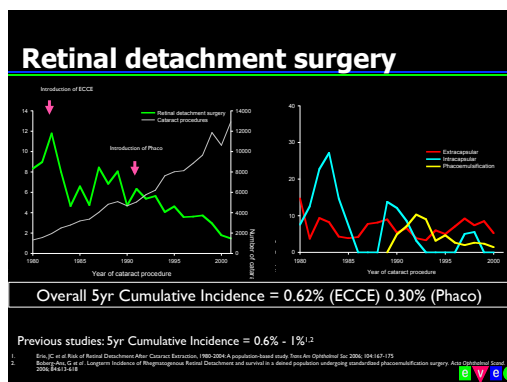
## Study Method

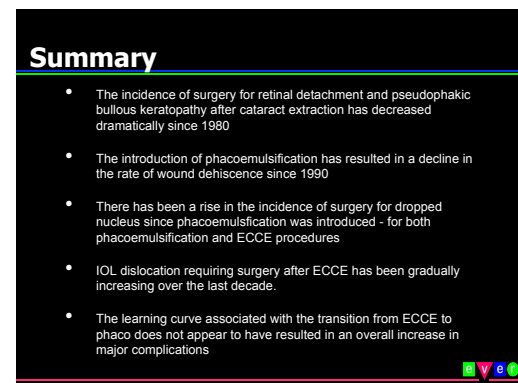
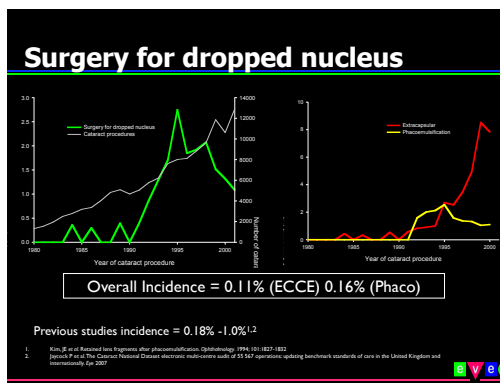
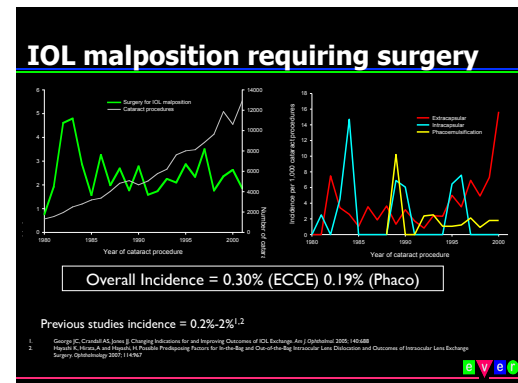
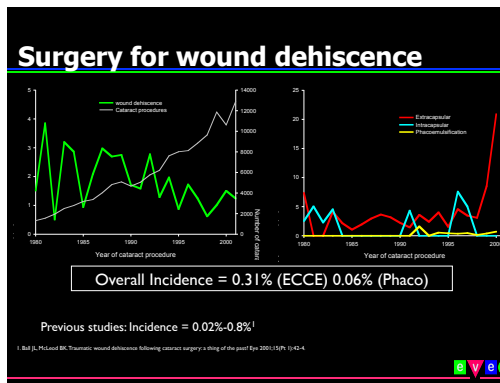
### WA Data Linkage System

- Hospital admissions 1980-2001
- Episodes of cataract surgery (n=130,008)
- Episodes of ocular surgery for:
  - Retinal detachment
  - Pseudophakic bullous keratopathy
  - Wound dehiscence
  - IOL Malposition
  - Dropped nucleus

### Validation of potential complications (n=~5,600)

- Extensive chart review (n=~9,000)
- Confirm complication
- Obtain cataract operation details





### **3.6. Media reports**

## Ophthalmology

## Comparing Pupillary Ruff Changes With IOP and Cup-to-Disc Ratio

Ophthalmology

Published May 2, 2012

In a comparative study, matching one patient eye to the fellow eye, Ang et al. compared pupillary ruff changes and associated gonioscopy findings with IOP and cup-to-disc ratio (CDR). They found an association between asymmetric intereye pupillary ruff changes and intereye asymmetry in both IOP and CDR in patients with glaucoma.

The study included 103 patients with a mean age of 64 years recruited from a glaucoma clinic population. Patients who had pseudofoliation or previous intraocular surgery or were currently taking IOP-lowering medication were excluded. The authors graded pupillary ruff and associated gonioscopy findings from photographs based on the pupillary ruff atrophy grading system. Study parameters included pupillary ruff absence and trabecular meshwork pigment, and trabecular meshwork pigment. The authors used Heidelberg Retinal Tomograph II imaging to determine how intereye differences in pupillary ruff correlated with intereye differences in IOP and CDR.



## Decrease in Subfoveal Choroidal Thickness After Ranzibumab

Ophthalmology

Published May 2, 2012

Yamazaki et al. found a decrease in subfoveal choroidal thickness in eyes with age-related macular degeneration that were treated over a 12-month period with intravitreal injections of ranibizumab. The authors suggest that ranibizumab may have a

pharmacologic effect on both choroidal neovascularization and the choroid under the neovascular lesion.

In this interventional case series, the authors treated 40 eyes with AMD with 0.5 mg injections of ranibizumab monthly for three months; patients received additional injections as needed over the following nine-month period. Subfoveal choroidal thickness in all 80 eyes was measured by OCT before and after starting the injections.

Results showed that the mean subfoveal choroidal thickness in all 40 eyes decreased from  $244 \pm 62 \mu\text{m}$  at baseline to  $234 \pm 66 \mu\text{m}$  at one month,  $226 \pm 68 \mu\text{m}$  at three months,  $229 \pm 67 \mu\text{m}$  at six months, and  $226 \pm 66 \mu\text{m}$  at 12 months. The rate of decrease in subfoveal choroidal thickness was  $18 \mu\text{m}/\text{year}$ , a rate greater than that reported in normal eyes.

According to the authors, these results suggest that ranibizumab affects the choroidal structure under the neovascular membrane in patients with AMD.

## Comparison of Adult Strabismus Surgery Outcomes

Ophthalmology

Published April 27, 2012

In an effort to better assess outcomes following adult strabismus surgery, Hatt et al. conducted a cohort study comparing the performance of motor, diplopia, and health-related quality of

cells/mm<sup>2</sup> to  $1,530 \text{ cells/mm}^2$ ; and CCT decreased from  $601 \mu\text{m}$  to  $521 \mu\text{m}$ . Refractive spherical equivalent was  $-4.3 \text{ D}$  preoperatively and  $0.9 \text{ D}$  at six months. At that same time point, 55 percent of eyes were within 1 D of emmetropia, and 77 percent were within 2 D of emmetropia. Refractive cylinder was  $-0.9 \text{ D}$  preoperatively and  $-1.5 \text{ D}$  at six months, while topographic cylinder was  $2.1 \text{ D}$  and  $1.7 \text{ D}$ , respectively.

The authors also measured a significant shift in topographic cylinder toward lower values between three and six months. Optimized spherical results were achieved by selecting IOLs based on a hyperopic shift of  $-0.75 \text{ D}$ .

## Scalability and Severity of Keratoconus in Children

JAMA Ophthalmology

July 5, 2012

Leoni-Mesplie found that, at diagnosis, keratoconus is often more advanced in children than in adults and that it exhibits faster disease progression.

In this retrospective study, the authors assessed the severity of keratoconus at diagnosis and its scalability over a period of two years in children and adults. In total, 216 patients were studied, comprising 49 patients (23 percent) under 15 years of age and 167 patients (77 percent) over 27 years of age at diagnosis. The authors assessed severity using Krumeich's classification and scalability using U.S. FDA criteria.

Keratoconus in children was significantly more severe at diagnosis with 28 percent—versus 8 percent of adults—having stage 4 disease. In addition, ophthalmoscopic signs were more frequent in children (43 percent versus 30 percent). The authors also found that mean values of maximum average and minimum keratometry as well as simulated keratometric astigmatism were higher. Keratoconus was not more likely to worsen in children than in adults; however, if progression did occur, it was faster and more severe in children, with significant differences in the spherical equivalent and

maximum and minimum keratometry. The authors concluded that early disease detection and close monitoring are crucial in young patients.

## Impact of Cataract on Vision-Specific Functioning

JAMA Ophthalmology

July 5, 2012

Cheew et al. determined that bilateral, but not unilateral, cataracts were significantly associated with poorer vision-specific functioning independent of refractive error. They also found that posterior subcapsular cataracts and cataract combinations had the greatest impact on vision-specific daily activities and that different cataract types caused poorer vision-specific functioning at different severity grades.

In this study, the authors examined 3,400 ethnically Indian patients aged 40 years or older living in Singapore. They assessed cataracts on slit-lamp examination and graded them according to the Lens Opacity Classification System (LOCS) III. The authors also determined vision-specific functioning scores using the Visual Function scale and validated these scores using Rasch analysis.

Two hundred sixty-nine (8 percent) and 780 (23 percent) study participants had unilateral or bilateral cataracts, respectively, and 329 (10 percent), 800 (25 percent), and 128 (4 percent) participants had nuclear, cortical, or posterior subcapsular cataracts, respectively.

The authors concluded that these findings have important implications for preoperative counseling and postoperative follow-up of cataract surgery patients, particularly younger patients and those who have complicated surgery.

## Incidence and Clinical Characteristics of Perinatal Infantile Hemangiomas

JAMA Ophthalmology

July 5, 2012

In a population-based study, Anilemi et al. reported the incidence, demographics, and clinical findings

## Journal Highlights

## Archives of Ophthalmology

## Risk and Incidence of Retinal Detachment After Phacemulsification

JAMA Ophthalmology

July 5, 2012

Clark et al. examined the risk factors for and long-term incidence of retinal detachment since the introduction of phacemulsification cataract surgery in Western Australia. Among other findings, the authors determined that the incidence of detachment after surgery has decreased significantly and that younger age and male sex were the most significant risk factors.

The authors used hospital administrative datasets from the Western Australian Data Linkage System to capture the entire cataract surgery cohort from the region.

After analyzing 65,055 phacemulsification operations performed there between 1989 and 2001, they identified 257 retinal detachments following surgery. The 10-year cumulative incidence of retinal detachment was 0.08 percent. The number of retinal detachments declined by an average of 19 percent for each year after 1989. The authors confirmed that younger age and male sex were significant risk factors for retinal detachment. Patients younger than 60 had four times the risk, and men had nearly double the risk. Anterior vitrectomy markedly increased the risk of retinal detachment, with a cumulative incidence at five years of 8.31 percent.

The authors concluded that these findings have important implications for preoperative counseling and postoperative follow-up of cataract surgery patients, particularly younger patients and those who have complicated surgery.

## Incidence and Clinical Characteristics of Perinatal Infantile Hemangiomas

JAMA Ophthalmology

July 5, 2012

In a population-based study, Anilemi et al. reported the incidence, demographics, and clinical findings





## Chapter 4

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# Evaluating blinding eye disease using other epidemiological methods

## Research Output

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### Published manuscripts

1. Clark A, Ng JQ, Morlet N, Mahendran P, Tropiano E, Spilsbury K, Preen DB, Semmens JB. **Quality of life after postoperative endophthalmitis.** *Clinical and Experimental Ophthalmology* 2008; 36(6):526-531.
2. Clark A, Morgan WH, Kain S, Farah H, Armstrong K, Preen DB, Semmens JB, Yu DY. **Diabetic retinopathy and the major causes of vision loss in Aboriginals from remote Western Australia.** *Clinical and Experimental Ophthalmology* 2010; 38(5):475-482.
3. Yuen J, Clark A, Ng JQ, Morlet N, Keeffe J, Taylor HR, Preen DB. **Further survey of Australian ophthalmologists' diabetic retinopathy management: did practice adhere to National Health and Medical Research Council guidelines?** *Clinical and Experimental Ophthalmology* 2010; 38(6):613-619.
4. Ting D, Ng JQ, Morlet N, Yuen J, Clark A, Taylor HR, Keeffe J, Preen DB. **Diabetic retinopathy management by Australian optometrists.** *Clinical and Experimental Ophthalmology* 2011; 39(3):230-235.
5. Ting D, Ng JQ, Morlet N, Yuen J, Clark A, Taylor HR, Keeffe J, Preen DB. **Diabetic retinopathy management by Australian GPs.** *Australian Family Physician* 2011; 40(4):233-238.
6. Crewe J, Morgan WH, Morlet N, Spilsbury K, Mukhtar SA, Clark A, Ng JQ, Crowley M, Semmens JB. **Assessing the diagnostic validity of a blind register** *Clinical and Experimental Ophthalmology* 2011; 39(6):494-500.
7. Crewe J, Morgan WH, Morlet N, Clark A, Lam G, Parsons R, Mukhtar A, Ng J, Crowley M, Semmens J. **Prevalence of blindness in Western Australia: a population study using capture and recapture techniques.** *British Journal of Ophthalmology* 2011; 96(4):478-481.
8. Kemp A, Preen DB, Morlet N, Clark A, McAllister IL, Briffa T, Sanfilippo FM, Ng JQ, McKnight C, Reynolds W, Gilles MC. **Myocardial Infarction After Intravitreal Vascular Endothelial Growth Factor Inhibitors: A Whole Population Study.** *Retina* 2013; 33(5):920-927.
9. Crewe J, Morlet N, Morgan WH, Spilsbury K, Mukhtar SA, Clark A, Ng JQ, Crowley M, Semmens JB. **Quality of life of the most severely vision-impaired.** *Clinical and Experimental Ophthalmology* 2011; 39(4):336-343.
10. Crewe J, M., Lam G., Clark A., Spilsbury K., Mukhtar A. S., Morlet N., Morgan W. H., Crowley M. and Semmens J. B. **Hospitalization rates of children who are blind.** *Clinical and Experimental Ophthalmology* 2013; 41(8):773-778.
11. Crewe JM, Morlet N, Morgan WH, Spilsbury K, Mukhtar AS, Clark A, Semmens JB. **Mortality and hospital morbidity of working-age blind.** *British Journal of Ophthalmology* 2013; 97(12):1579-1585.

### Published letters

1. Clark A, Morgan WH, Kain S, Farah H, Armstrong K, Preen DB, Semmens JB, Yu DY. **Diabetic Retinopathy in Australian Aboriginal people: response.** *Clinical and Experimental Ophthalmology* 2011; 39(2):185-186.
2. Ting DS, Morlet N, Clark A, Ng JQ, Yuen J, and Preen DB. **Differences in diabetic retinopathy management by primary eye care providers in Australia.** *Clinical & Experimental Ophthalmology* 2011; 39(6):585-586.
3. Ng JQ, Morlet N, Clark A, and Taylor HR. **Referral of diabetic macular oedema by Australian optometrists: response.** *Clinical & Experimental Ophthalmology* 2011; 39(9):924.

### Conference presentations

1. Kemp A, Preen DB, Morlet N, Clark A, McAllister IL, Briffa T, Sanfilippo F, Ng JQ, McKnight C, Reynolds W, Gilles MC. **Risk of adverse events following intravitreal vascular endothelial growth factor inhibitors: a whole-population study.** *International Data Linkage Conference* 2012, Perth, Australia. May 2012.
2. Kemp A, Preen D, Morlet N, Clark A, McAllister I, Briffa T, Sanfilippo F, Ng J, McKnight C, Reynolds W, Gilles MC. **Thromboembolic events following intraocular injections of VEGF-inhibitors: A whole-population study.** *Clinical and Experimental Ophthalmology* 2011; 39 (S1): 23-41
3. Ng J, Kemp A, Morlet N, Gillies M, Clark A, McAllister I, Preen DB. **Do VEGF Inhibitors Increase Myocardial Infarctions?** *Annual Meeting of the American Academy of Ophthalmology*, Orlando, USA. October 2011.
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6. Yuen J, Clark A, Ng JQ, Taylor HR, Preen DB. **National Ophthalmologists Survey for Diabetic Retinopathy Management: Does Current Practice Adhere to NHMRC Treatment Guidelines?** *Clinical and Experimental Ophthalmology* 2008; 36 (S2): A721-A722.

## 4.1. Background

While the utility of hospital administrative data in supporting longitudinal observational studies of cataract surgery outcomes in WA was demonstrated in Chapter 3, there are certain areas of health research where administrative databases alone are insufficient. These areas include, but are not limited to:

- 1) interventions or treatments that are not coded in administrative datasets or simply not recorded e.g. medications used 'off-label' or treatments outside of the health system;
- 2) populations under-represented or not represented in administrative datasets e.g. isolated, itinerate and minority populations;
- 3) studies where attitudes and knowledge are of interest e.g. physicians attitudes and knowledge regarding diabetic retinopathy screening and management;
- 4) studies of qualitative outcomes e.g. quality of life in value-based studies.

Other observational epidemiological methodologies may be used to augment or supplement the data found within health and other administrative databases. Together they may provide useful insights into the subjective impact of disease or adverse events, our gaps in knowledge about the services required, and the outcomes from treatments initiated or performed outside of the hospital system.

### 4.1.1. Clinical surveys

Clinical survey's employ a range of non-experimental observational or descriptive methods to characterise the presence or absence of a characteristic of interest in a defined group of people.<sup>302</sup> The researcher has full control over the data collected in a clinical survey, unlike research using administrative data where the researcher is beholden to the data custodians in terms of what variables are recorded. Clinical surveys therefore overcome many limitations of administrative datasets since they involve the direct collection of detailed clinical information on defined populations. The largest cross-sectional eye health surveys in Australia, the Melbourne Visual Impairment project and the Blue Mountains Eye study enrolled over 3,000 participants 49 years of age or older.<sup>14,15</sup> Similar large eye health surveys elsewhere included the Beaver

Dam<sup>303</sup> and Rotterdam<sup>304</sup> health studies. The sheer breadth of data collected regarding ocular health range from ocular history and examination to ocular biometry, allowing insight into disease prevalence, associations and outcomes of important blinding ophthalmic disease such as glaucoma, macular degeneration and cataract. However useful, large cross-sectional surveys such as these are generally limited by their expense.

Making use of survey questionnaires may also help to explain the reason why certain patterns are seen in linked health administrative data and therefore assist in formulating clinical practice policies that allow better care to be provided. Additionally, linkage to outcomes before and after surveys and interventions may provide a tangible measure of success or otherwise. For example, the endophthalmitis population study of WA involved a survey of Australian ophthalmologists to characterise current cataract surgery practice including use of chemoprophylaxis for endophthalmitis.<sup>305</sup> Another example is the Practice Styles and Preferences Survey of the American Cataract and Refractive Surgery (ACRS) membership that has been conducted yearly by Leaming since 1985 until 2012.<sup>306</sup>

#### **4.1.2. Quality of life**

The term 'quality of life' conveys "an overall sense of well-being, including aspects of happiness and satisfaction with life as a whole."<sup>307</sup> While conceptually this has meaning to most people, it is also entirely subjective and so challenging to measure. Understanding and measuring health-related quality of life goes beyond the traditional health measures of morbidity and mortality, which treats health as a rather uni-dimensional construct defined by the presence or absence of disease. While health has an impact on quality of life other aspects of life may have even greater impact e.g. social situation, relationships, religion and culture. Quality of life measures attempt to broaden our concept of health to include the physical and mental wellbeing of the population.

In ophthalmology research, standardised health-related quality of life measures are being increasingly used to support clinical decision-making. These value-based measures allow the impact of eye diseases and treatment outcomes to be

quantified taking into account patient perceptions that are not available in routine health administrative databases.<sup>308</sup>

That the measurement of quality of life is complex is reflected in the countless health-related quality of life instruments developed over the years. Many are disease specific and designed to reflect the unique impact of a specific disease upon a patients' health. In ophthalmology, a commonly used vision specific questionnaire is the 25-item visual function questionnaire developed by the National Eye Institute (NEI-VFQ25) as a reliable and well validated shortened version of their larger 51-item questionnaire.<sup>309</sup> This questionnaire attempts to measure the impact of vision on multiple dimensions of disease including social functioning and emotional wellbeing. In Australia the impact of vision impairment (IVI) questionnaire was developed as a validated 32-item tool that assesses the impact of vision dysfunction across 5 functional domains – leisure, household, social, mobility and emotional.<sup>310</sup>

Utilities values offer an alternative to function based assessments such as the VFQ-25 in deriving quality of life measures. They attempt to measure of a person's preference for a given health state, which may be interpreted as the quality of life associated with that health state. A utility value is conventionally defined on a continuum from 0.0 to 1.0; whereby 0.0 reflects the poorest health state e.g. death, and 1.0 the best e.g. perfect health. Thus the poorer the given health state the closer it is to 0.0. Utility values allow the impact of disease and intervention on quality of life to be compared across the health spectrum and not just ophthalmology.<sup>311,312</sup> Utility values also allow the calculation of the quality-adjusted life year (QALY) (calculated by multiplying the utility value for a given health state by the number of years spent at that health state). Attaching a dollar value to QALYs allows one to attach a dollar value to an intervention and guide expenditure of limited resources.<sup>313,314</sup>

Two main methods of calculating utility values are the time trade-off (TTO) and standard gamble methods. Both require the respondent to make a sacrifice for a given health state. The TTO method asks the participant with a given health state to consider their remaining years of life and then to state the number of years of their remaining they would be willing to give up to achieve perfect

health. The proportion of their remaining life they are willing to 'trade' for perfect health is subtracted from 1.0 to give the utility value. For example, a 60 year-old man with advanced glaucoma who expects to live until 90 is willing to give up 10 years (or 30%) of his remaining life to be glaucoma free, the utility value is 0.7 (1.0-0.3).<sup>314</sup> The standard gamble differs conceptually in that it requires the participant to consider a gamble that converts them to a perfect health state or immediate death. They are asked to consider a health state and then give the risk of immediate death they would accept to achieve a perfect health state, this risk is subtracted from 1.0. For example, a blind participant is willing to accept a 45% chance of immediate death to achieve perfect vision i.e the utility value is 0.55.<sup>314</sup>

#### **4.1.3. Project overviews**

The following is a background overview of each of the projects that were undertaken that together augment or supplement the information contained in health administrative databases to these specific research areas. Detailed methods are discussed in the papers relevant to each of the research areas. While each of the above projects are distinct in their own right, together they add to the knowledge of ophthalmic service outcomes for major blinding eye diseases in WA.

##### ***Post-marketing surveillance: arterial thromboembolic events after anti-VEGF for ARMD***

This WA study evaluated the risk of arterial thromboembolic events after anti-VEGF treatment for ARMD. ARMD is the leading cause of blindness in the developed world thanks mostly to increased life expectancy.<sup>315</sup> It is characterised by photoreceptor and retinal pigmented epithelium (RPE) atrophy at the macula leading to loss of central vision. There are two forms: a non-exudative ('dry') form, where central vision loss is gradual; and a neo-vascular ('wet') form, where vision loss is typically rapid.<sup>316</sup> Left untreated the prevalence of blindness is as high as 11.8% for ARMD patients over 80 years.<sup>315</sup> Dry ARMD treatment is currently limited to vitamin supplementation, which has a small effect in slowing progression.<sup>316</sup> The development of monoclonal antibody drugs that target VEGF has revolutionised the treatment of

neovascular ARMD where no treatment that could improve vision previously existed.<sup>317</sup>

The two anti-VEGF agents initially introduced, ranibizumab and bevacizumab, have been used in Australia for the treatment of the neovascular ARMD since 2005. Phase-III RCTs (ANCHOR<sup>18</sup> and MARINA<sup>19</sup>) demonstrated that intravitreal ranibizumab improves vision and vision-related quality-of-life in patients with wet-AMD when compared to photodynamic therapy (ANCHOR) and sham injection (MARINA). Ranibizumab is currently the only anti-VEGF agent licenced for use in neovascular ARMD in Australia. Prior to ranibizumab becoming available, bevacizumab was initially used off-label prior to as an intravitreal treatment for neovascular AMD based on the support of several case series.<sup>318,319</sup> It is also used as an alternative to ranibizumab in circumstances where patients do not fulfil the criteria for treatment under the Australian pharmaceutical benefits scheme. Two RCTs subsequently published in 2011 and 2012 (the CATT<sup>320</sup> and IVAN trials<sup>321</sup>) confirmed bevacizumab and ranibizumab are equivalent in effectiveness in reducing subretinal fluid and improving visual acuity.

Although the anti-VEGF agents have shown promising results, clinical trials have suggested they are possibly associated with the incidence of systemic arterial thromboembolic events (eg, acute myocardial infarction (AMI) and stroke). In the ANCHOR trial, the incidence of AMI at 12 months was 2.1% in the VEGF-inhibitor treatment group compared with 0.7% in the control group,<sup>18</sup> while stroke occurred in 0.7% of both the treatment and control groups.<sup>18</sup> At two years of follow-up, the MARINA trial reported an incidence of 1.3% for AMI and 2.5% for stroke after intravitreal ranibizumab, compared with 1.7% and 0.8% for AMI and stroke respectively in controls.<sup>19</sup> The risk of arteriothrombotic adverse events was between 2-3% in CATT trial and <2% in IVAN the IVAN trial, both trials found there was no significant difference between ranibizumab and bevacizumab in the risk of arteriothrombotic events.<sup>320,321</sup>

However, to date, no population-based investigation of the possible thromboembolic risk associated with either ranibizumab or bevacizumab has

been undertaken. Given the sharp initial increase in utilisation of this treatment,<sup>317</sup> research of this nature is needed.

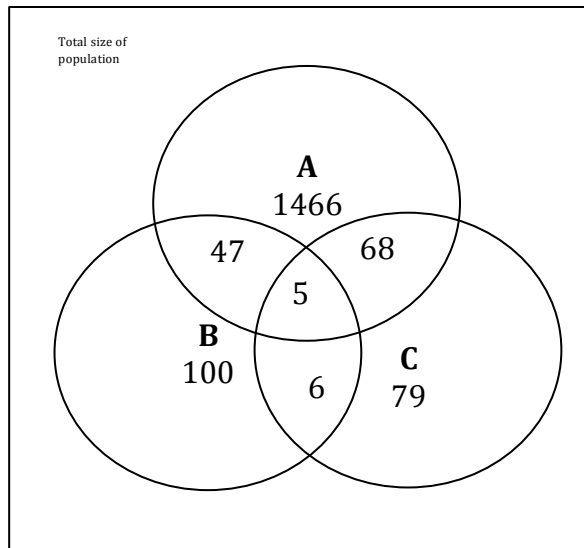
As bevacizumab continues to be used off-label, it is not recorded in available administrative datasets. Additionally, bevacizumab may also be given for other indications including diabetic maculopathy and retinal vein occlusion, which is also not recorded in administrative datasets. This study highlights the utility in linking disease specific databases and registries with other health administrative databases. It required this information be obtained from alternative sources – namely the intravitreal injection databases and logbooks from the individual retinal clinics performing these injections in WA. Linkage of injection logbook data with the HMDC allowed analysis of the risk of subsequent arterial thromboembolic events via hospital admissions.

***The Epidemiology of Blinding Eye Disease study (EBEDS)***

Blindness is a crippling disability resulting in misery, loss of employment, economic loss and premature death. It is estimated that around 50,000 (0.57%) Australians are known to be blind,<sup>322</sup> with an incidence 4.5 times higher amongst indigenous groups.<sup>323</sup> Blindness rates are predicted to rise markedly in the next 20 years, owing largely to the ageing of the developed world's population.<sup>324</sup> Currently, no accurate or validated population data on blindness exists anywhere in the world.<sup>325</sup>

Existing prevalence of blindness data in the population is based on small population samples,<sup>325</sup> or voluntary blindness registries.<sup>326</sup> Trends in blindness incidence are only derived from blind registries but there are the attendant problems of case ascertainment and diagnostic inaccuracy.<sup>324,325</sup> Measurements of voluntary registration rates in the United Kingdom indicate that about 70% of legally blind persons are registered.<sup>327</sup> More recent work there found that 68% were registered but 34% of the registered blind were in fact not legally blind when re-examined.<sup>328</sup>





**Figure 4-1** - The three lists and distribution of participants in the capture-recapture study of blindness prevalence in Western Australia.

There are a number of methods to determine the total burden of disease in a community. A simple combination of multiple lists with details of the disease in question may obtain prevalence data. However, this is prone to underestimating true prevalence.<sup>329</sup> Sequential population-based sampling techniques have previously been attempted but this is very

expensive, labour intensive and requires a stable and consistent population. A principal fault is that any results cannot be extrapolated to the whole population since an isolated sample population is rarely representative of the whole population. Capture – recapture techniques may be used to accurately determination of disease prevalence in a relatively efficient and inexpensive way. Others have used this technique to measure prevalence of stroke,<sup>330</sup> dementia,<sup>331</sup> and varicella zoster<sup>332</sup>.

Capture-recapture involves measuring the dilution of a target population within the broader population. The acquisition of two or more independent sources of disease registration within the one population is required, and then dilution mathematics is used to calculate prevalence and confidence intervals. Because no two lists can be truly independent three lists are preferred to allow the calculation of dependence between lists.<sup>333,334</sup> In the case of diabetes, the three list capture-recapture approach found that prevalence was 100% greater than that calculated by list summation.<sup>334</sup>

During EBEDS the diagnostic accuracy of the WA blind register (held by the Association for the blind of WA (ABWA)) in determining legal blindness<sup>1</sup> and its cause was validated. Subsequently capture-recapture techniques were used to

<sup>1</sup> Legal blindness in Australia is defined as having a best corrected visual acuity of LogMAR greater than 1 (Snellen less than 6/60) or a visual field restriction of less than 10 degrees from central fixation or a combination of reduced visual acuity and field loss resulting in an equivalent level of disability in the better eye.

calculate a population-based prevalence of blindness in WA. Three capture lists were generated in this study to calculate blindness prevalence in WA (Figure 4-1). The first (A) was derived from the blind register. The second list (B) was generated over a defined period and comprised all legally blind patients attending routine appointments, either at public hospital outpatient eye clinics, or at selected ophthalmologists and optometrists clinics. The final list (C) was generated over a separate defined period and comprised all legally blind patients attending either a tertiary hospital outpatient eye clinic, a consultant ophthalmologist's rooms, or selected general medical practitioner clinics. Relationships between the 3 lists were analysed using log-linear modelling in which the logarithm of the expected frequency is expressed as a linear function of effects and interaction terms.<sup>335,336</sup> Detailed statistical methodology is presented in the published papers.

Once a validated list of blind-registered people in WA was created, then data integration techniques allowed the study of health outcomes of the validated ABWA registered blind cohort through linkage to hospital administrative and mortality data using the WADLS.

#### ***Aboriginal eye health***

The Aboriginal communities in the eastern Goldfields region of WA are extremely isolated with poor access to health care (Figure 4-2).<sup>337</sup> This remoteness, combined with cultural barriers to health care, means there are potentially a large proportion of the Aboriginal community who are not captured in hospital administrative datasets until late in the disease process when hospital care is inevitable. They represent an important and vulnerable population that, due to their lack of access to health care facilities, is not adequately represented in the WADLS.

Eye health among Aboriginal Australians first gained national attention in the mid-1970s as a result of The National Trachoma and Eye Health Program (NTEHP).<sup>338</sup> It found that the prevalence of eye disease among Aboriginal Australians was up to ten-times greater than the non-Aboriginal Australian population and that blindness was up to twice as common, with the majority of this vision loss being due to preventable or treatable conditions.<sup>339</sup> More recent



**Figure 4-2** The Eastern Goldfields Eye Health Survey area, Western Australia (reprinted with permission)

studies show that vision loss in Aboriginal people is still the result of preventable or easily treated conditions such as cataract, diabetic retinopathy (DR), uncorrected refractive error, trachoma and trauma.<sup>340,341</sup> They tend to be more common and severe in regional communities where factors such as access to health care, poor housing, poor diet and poor sanitation may play a role.<sup>342</sup>

The Goldfields Eye Health Survey examined trends in diabetic retinopathy and causes of vision loss. Clinical and demographic data from ophthalmic examinations performed during yearly clinics in Aboriginal communities of the Eastern Goldfields region of WA were collated into a clinical database. This registry formed a comprehensive dataset of Aboriginal eye health in the region over a 12-year period not available through the HMDC. This study highlights how survey methodologies may be used to fill in the gaps in knowledge regarding the health of itinerate and isolated populations who are under-represented in health administrative databases. The data from such surveys may be linked to administrative datasets in outcomes studies e.g. Busselton health study.<sup>66</sup>

#### ***Diabetic retinopathy screening and management practices***

Diabetic retinopathy is a national health priority. It is the fourth major cause of blindness in the Australian community and one of the most common complications of diabetes.<sup>10</sup> The contribution of diabetic retinopathy to the burden of blindness in the Australian community is expected to worsen as the number of Australians with diabetes doubles over the next two decades.<sup>343-345</sup>

Fortunately vision loss from diabetic retinopathy is preventable in up to 98% if detected early and managed appropriately.<sup>346</sup> The predicted rising burden of diabetes and diabetic retinopathy therefore needs to be met with improvement in early detection and appropriate management if significant visual burden in the community is to be minimised.

The Australian National Health and Medical Research (NH&MRC) guidelines for diabetic retinopathy screening and management provide a comprehensive and prescriptive outline for best practice,<sup>347</sup> yet only half of diabetics are adequately screened.<sup>348-352</sup> The reasons for this aren't immediately apparent. Perhaps the link between early detection through screening and prevention of blindness due to diabetes is not adequately emphasised so people with diabetes aren't motivated to attend regular eye checks. Alternatively, eye care providers may not refer their patients as regularly as they report. These questions cannot be evaluated using administrative datasets.

This study involved a national survey of ophthalmologists, optometrists and general practitioners (GP) regarding their diabetic retinopathy screening and management practices. The survey questionnaire ([Appendix 2](#)) was administered during November 2007 and February 2008 to a random selection of ophthalmologist, optometrist and GPs. This survey was conducted after the release of the NH&MRC guidelines for diabetic retinopathy screening and management, with the aim of measuring their impact by comparison with similar surveys done prior.<sup>353-358</sup> The results were collated, analysed and reported by the co-authors under the candidates close guidance.

***Quality of life after post-operative endophthalmitis and in the severely vision-impaired***

Quality of life was explored across two separate studies. The first explored the impact of a major blinding event, postoperative endophthalmitis, on patient quality of life. While visual acuity is the most commonly reported outcome measure in studies investigating postoperative endophthalmitis,<sup>272,293,359,360</sup> it cannot describe the impact of endophthalmitis upon a patients overall quality of life where social interaction, mental health, dependency and functional ability play an important role. By determining the quality of life in patients with endophthalmitis, the personal burden imposed by this condition can be

estimated including a more accurate estimate of the true cost (in a dollar sense) of endophthalmitis beyond simply the cost to the health care system.

Quality of life was evaluated in this study using three validated quality of life questionnaires. The first was the National Eye Institute's VFQ-25 questionnaire,<sup>309</sup> which measures self reported patient perceptions of vision and health-related quality of life. The second was the EuroQol EQ-5D (EQ-5D)<sup>361</sup> questionnaire that measures general health-related quality of life; and the final tool was the TTO method to allow calculation of utility values.<sup>362</sup>

In EBEDS, quality of life associated with severe vision impairment was described using the IVI questionnaire and TTO methodology. The questions were administered in an interview conducted during the validation clinics held to validate the blind register. The study coordinator, Ms Julie Crewe, administered all questionnaires to maintain consistency across responses.

## **4.2. Research output**

### ***Published manuscripts***

This chapter includes 10 papers published in the peer-reviewed literature addressing the research areas discussed above: one paper describes the risk of arterial thromboembolic events after anti-VEGF treatment; 4 papers describe the findings from EBEDS; one paper describes trends in diabetic retinopathy and the causes of vision loss in Aboriginals from the Eastern Goldfields; three papers describe the diabetic retinopathy screening and management practices of Australian ophthalmologists, optometrists, and GPs respectively; and two paper describe quality of life in post-operative endophthalmitis and severe vision impairment respectively.

### ***Research Translation***

Research findings arising from this chapter were presented at local and national conferences.

The study evaluating thromboembolic events after anti-VEGF treatment has formed a pilot project for a large national post-marketing surveillance study to fully assess the systemic safety of intravitreal anti-VEGF treatment –the fight retinal blindness (FRB) project.<sup>363</sup>

### **4.3. Published manuscripts**

Kemp A, Preen DB, Morlet N, **Clark, A**, McAllister IL, Briffa T, Sanfilippo FM, Ng JQ, McKnight C, Reynolds W, Gilles MC. **Myocardial Infarction After Intravitreal Vascular Endothelial Growth Factor Inhibitors: A Whole Population Study.** *Retina* 2013; 33(5):920-927.

# MYOCARDIAL INFARCTION AFTER INTRAVITREAL VASCULAR ENDOTHELIAL GROWTH FACTOR INHIBITORS

## A Whole Population Study

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**Purpose:** To determine the risk of thromboembolic and gastrointestinal bleeding events in the 12 months after injections of bevacizumab or ranibizumab compared with photodynamic therapy and a nontreated community sample.

**Methods:** Hospital and death records were examined for 1,267 patients treated with vascular endothelial growth factor inhibitor and 399 patients treated with photodynamic therapy attending Western Australian eye clinics from 2002 to 2008, and 1,763 community controls, aged  $\geq 50$  years. Hospital records from 1995 to 2009 were analyzed for history of myocardial infarction (MI), stroke, and gastrointestinal bleeding before treatment. Records were searched for evidence of these events in the 12 months after treatment.

**Results:** The 12-month MI rate was higher for vascular endothelial growth factor inhibitor patients than photodynamic therapy patients and the community group (1.9/100 vs. 0.8 and 0.7, respectively). No differences were observed between patients treated with bevacizumab and ranibizumab. The adjusted MI rate was 2.3 times greater than the community group (95% confidence interval, 1.2–4.5) and photodynamic therapy rate (95% confidence interval, 0.7–7.7). The 12-month MI risk did not increase with the number of injections administered (hazard ratio, 0.9; 95% confidence interval, 0.5–1.5). Stroke and gastrointestinal bleeding did not differ between any exposure groups.

**Conclusion:** Although all the adverse events examined were rare, patients treated with vascular endothelial growth factor inhibitors were significantly more likely to experience fatal or nonfatal MI than the community group. This increased risk may be related to the underlying age-related macular degeneration or vascular endothelial growth factor inhibitor use itself.

RETINA 33:920–927, 2013

The vascular endothelial growth factor (VEGF) inhibitor drugs, bevacizumab and ranibizumab, are effective in treating neovascular age-related macular degeneration (AMD), with many patients experiencing improvements in vision and quality of life.<sup>1–4</sup> Use of these therapies has grown rapidly in recent years<sup>5</sup> and is used for AMD treatment in the United States and elsewhere.<sup>5–7</sup> These medications are known to increase the risk of arterial thromboembolic events (e.g., myocardial infarction [MI] and stroke) when used systemically,<sup>6</sup> but much smaller doses are administered through localized intravitreal injection for neovascular AMD,<sup>7</sup> and it is unknown whether this would increase the risk of

thromboembolic events for patients with, or without, a history of these events.<sup>7</sup>

The MARINA<sup>1</sup> and ANCHOR<sup>4,8</sup> Phase III trials investigating the efficacy of VEGF inhibitors for neovascular AMD reported a small trend toward increased arterial thromboembolic events in patients treated with ranibizumab.<sup>1,4,8</sup> In the ANCHOR trial, the incidence of acute MI at 24 months was 2.2% in the VEGF inhibitor treatment group compared with 1.4% in the control group,<sup>8</sup> whereas stroke occurred in 1.1% and 1.4% of the treatment and control groups, respectively.<sup>9</sup> At 2 years of follow-up, the MARINA trial reported an incidence of 1.3% for MI and 2.5%



for stroke after intravitreal ranibizumab treatment compared with 1.7% and 0.8% for MI and stroke, respectively, after placebo<sup>10</sup> When 12-month data from 3 trials (MARINA, ANCHOR, and PIER) were combined, the overall incidence of arterial thromboembolic events was higher for patients treated with ranibizumab (2.5%) compared with controls (1.1%).<sup>5</sup>

Photodynamic therapy (PDT), a commonly used treatment for neovascular AMD before 2006, is not known to increase the risk of arterial thromboembolic events.<sup>5,10</sup> Gastrointestinal (GI) bleeding was reported in 0.8 per 100 patients treated with ranibizumab compared with no events among PDT patients.<sup>9,11</sup> Those clinical trials individually had insufficient power to statistically evaluate low-incidence events, leading researchers to comment that the clinical significance of the noted adverse events is unclear and requires further attention.<sup>4,12</sup>

A retrospective study of 146,942 Medicare beneficiaries in the United States observed patients for 12 months after treatment with ranibizumab, bevacizumab, pegaptanib, or PDT.<sup>5</sup> After statistical adjustment, patients treated with ranibizumab were found to have a *reduced* risk of MI compared with PDT patients (hazard ratios [HR], 0.78; 95% confidence interval [CI], 0.62–0.98).<sup>5</sup> No differences in MI rates were observed between any other exposure groups, and no differences in rates of stroke or GI bleeding were reported between groups.<sup>5</sup>

To date, no study has compared the risk of thromboembolic events after these therapies with that in the general population or examined the effect of previous thromboembolic events on risk after VEGF inhibitor treatment. Such comparisons are important, given the mixed evidence for underlying risk of thromboembolic events in patients with AMD<sup>13–17</sup> and in the large number of patients using these therapies.<sup>5</sup> We used whole population–linked medical/health data to deter-

mine whether AMD patients treated with intravitreal injections of bevacizumab or ranibizumab had an increased risk of thromboembolic events compared with AMD patients treated with PDT and a community sample without neovascular AMD. Our study may be viewed as a Phase IV pharmacovigilance method of evaluating the thromboembolic adverse effects of VEGF inhibitors in a real-world population.

## Methods

A matched multiple-comparison cohort was retrospectively studied using whole-population routinely collected health/medical data to determine the risk of thromboembolic events after intravitreal treatment with bevacizumab or ranibizumab. Ethical approval was provided by the University of Western Australia (WA) and the WA Department of Health.

## Exposure Groups

Three groups of individuals aged  $\geq 50$  years from WA were examined: 1) VEGF inhibitor patients, 2) PDT patients, and 3) a community comparison group without neovascular AMD. All VEGF inhibitor patients were treated for AMD between January 1, 2006, and December 31, 2008. All of the PDT group also had AMD and were treated from January 1, 2002, to December 31, 2007. The PDT group was identified over an earlier and longer time period because of the diminishing use of this treatment in recent years.<sup>5</sup> The VEGF inhibitor and PDT groups were identified from routinely recorded treatment information maintained by the four eye clinics providing these treatments in WA during the study period. We tested the null hypothesis of no difference between groups using separate one-way comparisons for each of the outcomes of interest.

The community group was randomly selected from a pool of eligible adults (aged  $\geq 50$  years) listed on the WA Electoral Roll who had no record of treatment with ranibizumab, bevacizumab, or PDT from 2002 to 2008. People in the eligible pool were matched to the VEGF inhibitor group by gender, 5-year age group, and socioeconomic status and residential location, both of which were based on geocodes.

## Outcome Ascertainment

Eye clinic records were linked to health outcome data through the WA Data Linkage System (WADLS), maintained by the WA Department of Health.<sup>18</sup> The WADLS combines eight core data sets including

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hospital admissions, deaths and Electoral Roll registrations, dating back variously to 1966.<sup>18</sup> The system is updated continuously, and the quality of linkage has been assessed by comparison of routine linkage to clerical investigation, with average proportions of invalid links (false positives) and missed links (false negatives), both estimated at 0.11%.<sup>18</sup> Hospital data were linked for all individuals from January 1, 1995, to December 31, 2009. Demographic information (i.e., age, sex) and data relating to primary and coexisting diagnoses were extracted from the hospital data set. Geocodes available in the hospital and mortality data sets were used to attach social disadvantage (Socio-Economic Indexes for Areas) and geographic remoteness (Accessibility/Remoteness Index of Australia) to all records.<sup>19,20</sup>

The outcomes of interest were MI, stroke, and GI bleeding listed in the principal discharge diagnosis field of a hospital admission record (nonfatal) or as the cause of death identified using the International Classification of Diseases version 10 with Australian Modifications (ICD-10-AM: MI I21.0–I22.9, stroke I163.0–I163.9, GI bleeding K92.2).<sup>21</sup> To be consistent with other studies, we examined the rates of admission and death for 12 months after the treatment for all individuals.<sup>5,22</sup>

Follow-up for VEGF inhibitor and PDT patients commenced on the first (index) recorded date for treatment. Individuals who received both PDT and VEGF inhibitors ( $n = 126$ ) (in all instances, use of these two treatments was consecutive rather than concomitant) were considered VEGF inhibitor-only patients if their VEGF inhibitor treatment commenced before PDT ( $n = 3$ ) or their first PDT treatment was within 12 months of subsequently commencing VEGF inhibitor treatment ( $n = 37$ ). Patients first treated with PDT and with a minimum of 12 months between their index PDT date and index VEGF inhibitor date were considered to be both VEGF inhibitor and PDT patients, with separate follow-up periods used in each instance ( $n = 86$ ). The community group were randomly assigned index dates in accordance with the index treatment dates of the VEGF inhibitor group. This method, used elsewhere,<sup>23</sup> ensured a comparable 12-month period for the community group to observe MI, stroke, and GI bleeds. Follow-up ended at 12 months after the index date, death, or the date of the first recorded admission, whichever occurred first. Follow-up was censored if the outcomes of interest, fatal or nonfatal, did not occur by the end of the follow-up period.

Individuals with prior MI, stroke, GI bleed, or diabetes were identified from International Classification of Diseases codes of these conditions in any of the discharge diagnosis fields in the hospital data set

during the period from January 1, 1995, to the index treatment.

### Statistical Analyses

Patients' demographic characteristics at index treatment were compared for all groups. Chi-squared and one-way analysis of variance tests were used to compare the differences between groups for categorical and continuous variables, respectively.

The 12-month rate of fatal or nonfatal MI, stroke, and GI bleeding was calculated for all groups using person-time at risk as the denominator. We also separately calculated the rates for patients treated with bevacizumab or ranibizumab. Given the low number thromboembolic events, two-tailed Fisher exact tests were used to compare groups. The patients treated with bevacizumab and ranibizumab were subsequently analyzed as one VEGF inhibitor group because no differences in events were detected between patients treated with these drugs. No further analyses were conducted for stroke or GI bleeding because the Fisher exact test did not identify any differences between the groups. In addition, there were too few stroke or GI bleed events to undertake regression modeling,<sup>24</sup> especially when adjusting for covariates.

Cox proportional hazards regression was used to calculate the hazard ("risk") of MI in the 12 months after treatment with VEGF inhibitors or PDT and the equivalent observation period for the community group. Models were adjusted for sex, age, and history of MI or diabetes. Survival time to fatal or nonfatal MI for the community group was compared with survival for VEGF inhibitor patients. For each variable in the Cox models, the proportional hazards assumption was tested visually using Kaplan-Meier curves and by examining a plot of  $-\log(-\log(\text{survival time}))$  against  $(\log)\text{time}$ .

Number needed to harm (NNH) analysis was performed to quantify any increased risk of MI in patients treated with VEGF inhibitors compared with PDT patients and the community group. The NNH estimates and 95% CIs were calculated as the inverse of the absolute risk increase ( $\text{NNH} = \frac{1}{\% \text{MI VEGF inhibitor group} - \% \text{MI community group}}$ ).<sup>25</sup> All analyses were performed using PASW (formerly SPSS) version 17.0.<sup>26</sup>

### Results

Characteristics of the study participants are shown in Table 1. The groups were generally well matched, but the community group was 2 years younger, on

Table 1. Demographic and Treatment Characteristics of Patients Treated with Intravitreal Injections of Bevacizumab and Ranibizumab, PDT Patients, and Community Controls

	VEGF Inhibitor	PDT	Community	<i>P</i>
Total number	1,267	399	1,763	—
Male, %	40	48	45	0.083
Age at index, years*	79.1 (8.0)	78.7 (8.4)	77.0 (9.6)	<0.001†
SEIFA score‡	6.9 (2.2)	7.0 (2.2)	6.9 (2.1)	0.684
Residence, %				
Major cities	61	62	58	0.587
Inner regional	28	28	30	
Outer regional	8	7	8	
Remote	3	3	4	
History, %				
Diabetes	15.2	12.8	12.1	0.052§
MI	5.5	3.3	6.0	0.203
Stroke	4.7	4.8	7.5	<0.001¶
GI bleed	4.3	2.3	4.3	0.139
Index date	Jan 20, 2006, to Dec 24, 2008	Jan 11, 2002, to Aug 24, 2007	Jan 17, 2006, to Dec 24, 2008**	—
Treatment duration days	199 (218)	244 (231)	—	0.001
Days between treatments	39 (40)	64 (51)	—	<0.001
No. treatments	4.1 (2.8)	3.2 (1.7)	—	0.001
Bevacizumab	792	—	—	—
Ranibizumab	475	—	—	—

\*Values are represented as mean (SD).

†The community group was significantly younger than VEGF inhibitor patients ( $P < 0.001$ ) and PDT patients ( $P = 0.003$ ).

‡Socio-Economic Indices For Areas, range 0 (high disadvantage) to 10 (low disadvantage).

§History of diabetes was more common in the VEGF inhibitor patients compared with the community ( $P = 0.017$ ).

¶History of stroke was more common in the community group than in VEGF inhibitor patients ( $P = 0.002$ ).

\*\*Pseudo-dates (see the "Methods" section).

average, than the VEGF inhibitor patients ( $P < 0.001$ ) and PDT controls and was more likely to have a history of stroke (7.5% vs. 4.7% and 4.8%, respectively;  $P = 0.002$ ). PDT patients were treated over a longer period than VEGF inhibitor patients (244 days vs. 199 days,  $P < 0.001$ ) and had an additional 25 days between treatments on average ( $P < 0.001$ ). Vascular endothelial growth factor inhibitor patients received slightly more treatments, on average, than PDT patients.

The rate of adverse events among treated groups is shown in Table 2. Stroke and GI bleeding rates across groups were very low, and rates for MI were low (stroke: 0.3–0.8/100, GI bleeds: 0.0–0.6/100, MI: 0.7–2.1/100 patients). The rates for stroke and GI bleeding did not differ between treated groups, and no significant differences were observed between patients with bevacizumab and ranibizumab. The difference between the MI rate for VEGF inhibitor patients and the community group was significant (1.9 vs. 0.7/100,  $P = 0.01$ ). The rate for PDT patients, however, did not differ significantly from that in the VEGF inhibitor group (0.8 vs. 1.9/100,  $P = 0.14$ ).

Patients treated with VEGF inhibitors had approximately 2.3 to 2.5 times the risk of MI than the

community group in the unadjusted model (95% CI, 1.3–4.9) and after adjustment for prior MI, diabetes, sex, and age (95% CI, 1.2–4.5) (Table 3). Similar HRs were found for VEGF inhibitor patients compared with the PDT group; however, these were not significant in the unadjusted (HR, 2.3; 95% CI, 0.7–8.1) or adjusted models (HR, 2.4; 95% CI, 0.7–7.7). In the VEGF inhibitor group, risk of MI did not increase with each additional treatment received (HR, 0.9; 95% CI, 0.5–1.5, not shown).

For every 93 patients treated with VEGF inhibitors, an additional MI would occur over and above the community rate (Table 3). Survival time to MI for the VEGF inhibitor and community groups is shown in Figure 1. Although the difference in survival curves was statistically significant (HR, 2.3; 95% CI, 1.2–4.5), this represented a small difference in survival probability at 12 months.

## Discussion

By using whole-population routinely collected health/medical data from an Australian state of 2.3 million people,<sup>27</sup> we determined the risk of thromboembolic

Table 2. Number of Adverse Events in the 12 Months After Index Treatment for Bevacizumab and Ranibizumab Patients, PDT Patients, and the Community Group

	Bevacizumab	Ranibizumab	VEGF Inhibitor (Total)	PDT*	Community	Fisher Exact Test (P)
MI, n (%)						
Nonfatal	8 (1.0)	8 (1.7)	16 (1.3)	3 (0.8)	9 (0.5)	Bevacizumab vs. ranibizumab (0.66)
Fatal	5 (0.6)	2 (0.4)	7 (0.6)	0 (0.0)	4 (0.2)	VEGF inhibitor vs. photodynamic (0.14)
Total	13 (1.6)	10 (2.1)	23 (1.9)	3 (0.8)	13 (0.7)	VEGF inhibitor vs. community (0.01)
Stroke, n (%)						
Nonfatal	2 (0.3)	2 (0.4)	4 (0.3)	3 (0.8)	8 (0.5)	Bevacizumab vs. ranibizumab (0.63)
Fatal	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	VEGF inhibitor vs. photodynamic (0.37)
Total	2 (0.3)	2 (0.4)	4 (0.3)	3 (0.8)	8 (0.5)	VEGF inhibitor vs. community (0.77)
GI bleed, n (%)						
Nonfatal	4 (0.5)	3 (0.6)	7 (0.6)	0 (0.0)	7 (0.4)	Bevacizumab vs. ranibizumab (0.53)
Fatal	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	VEGF inhibitor vs. photodynamic (0.21)
Total	4 (0.5)	3 (0.6)	7 (0.6)	0 (0.0)	7 (0.4)	VEGF inhibitor vs. community (0.59)
MI or stroke, n (%)						
Total	15 (1.9)	12 (2.5)	27 (2.1)	6 (1.5)	21 (1.2)	Bevacizumab vs. ranibizumab (0.29)
						VEGF inhibitor vs. photodynamic (0.29)
						VEGF inhibitor vs. community (0.03)
MI, stroke or GI bleed Total, n (%)	19 (2.4)	15 (3.2)	34 (2.7)	6 (1.5)	28 (1.6)	Bevacizumab vs. ranibizumab (0.26)
						VEGF inhibitor vs. photodynamic (0.12)
						VEGF inhibitor vs. community (0.03)

\*Photodynamic therapy.

events in the 12 months after treatment with VEGF inhibitors compared with PDT patients and a non-treated community group. The 12-month rate for MI, stroke, and GI bleed was low in all exposure groups, consistent with rates in the general population for  $\geq 50$ -year-olds (MI: 1.1/100 person-years,<sup>28</sup> stroke: 0.2/100 person-years,<sup>29</sup> GI bleeds: 0.1/100 person-years).<sup>30</sup> We observed no significant differences in the rates of MI, stroke, or GI bleeding between patients treated with bevacizumab or ranibizumab (1.6 and 2.1 events/100 persons, respectively). No differences in the 12-month rate of stroke or GI bleeding were found between groups.

Previous studies reported no differences in stroke or bleeding between VEGF inhibitor and PDT patients but did report significantly lower MI incidence (1.1 vs. 1.3/100 person-years) for ranibizumab compared with

PDT.<sup>5</sup> The reported incidence of MI was similar to that in our study; however, Curtis et al did not adjust for socioeconomic differences between exposure groups. Their study was conducted in the United States where ranibizumab is more expensive than PDT. The authors suggest that socially disadvantaged patients may have been more likely to receive PDT, accounting for the difference in rates of MI.<sup>5</sup> Such differences between exposure groups did not occur in our study, as the exposure groups were well matched for socioeconomic status and costs were similar across groups.<sup>31,32</sup> During the study period, ranibizumab was available to social security recipients for A\$4.90 and to other Australian residents for \$30.70. Bevacizumab was not publically subsidized during the study period and cost approximately \$50 per treatment. PDT was fully subsidised for social security

Table 3. Results from Cox Proportional Hazards Regression Comparing Risk (and 95% CIs) of MI in the 12 Months After Index Treatment and Number Needed to Harm for Bevacizumab and Ranibizumab Patients, PDT Patients, and the Community Group

Exposure Groups	Unadjusted HRs	Adjusted HRs*	Number Needed to Harm
VEGF inhibitors vs. community	2.47 (1.25–4.87) <i>P</i> = 0.01	2.29 (1.16–4.54) <i>P</i> = 0.02	93 (52–414)
VEGF inhibitors vs. PDT	2.44 (0.73–8.14) <i>P</i> = 0.15	2.32 (0.70–7.74) <i>P</i> = 0.17	97 (52–∞)†
PDT vs. community	1.02 (0.29–3.58) <i>P</i> = 0.89	0.97 (0.28–3.43) <i>P</i> = 0.96	6,896 (142–∞)

\*Models included age, sex, history of MI, and history of diabetes.

†The CIs spanning infinity indicate nonsignificant estimates for number needed to harm.<sup>25</sup>

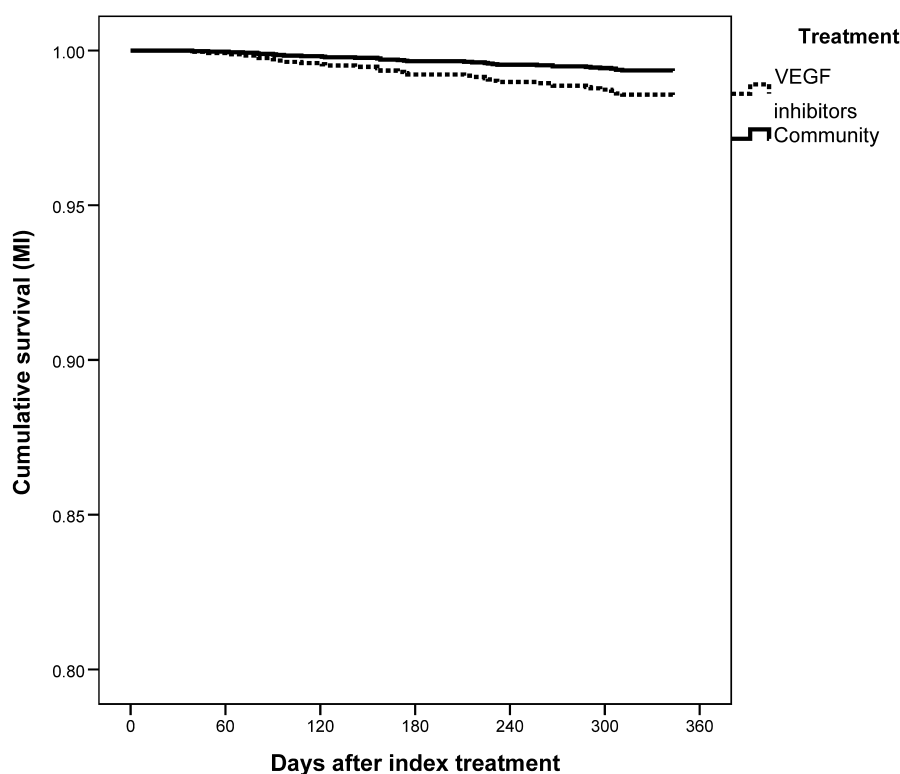
recipients and cost approximately \$50 for other patients.<sup>31,32</sup>

Although MI was rare, we observed statistically significant differences between treated groups. Compared with the community group, patients receiving VEGF inhibitors were 2.3 times more likely to have a MI. This equates to an additional MI for every 93 patients treated, over and above the community rate.

Two explanations may account for the increased MI rate we observed, namely MI risk may be increased by VEGF inhibitors themselves (i.e., a drug effect) or the underlying condition (i.e., AMD). If AMD were associated with MI,<sup>14</sup> both VEGF inhibitor and PDT patients should have higher MI rates than the

community group. We found a significantly increased MI hazard for VEGF inhibitor patients than the community group but not for PDT patients. If VEGF inhibitors themselves increased MI, a higher hazard among VEGF inhibitor patients than both the community and PDT groups would be expected. Although significant differences existed between the VEGF inhibitor and community groups, none were found between VEGF inhibitor and PDT patients.

Despite including all PDT patients in WA over 7 years, the number of patients in this group was comparatively small (*n* = 399). A minimum PDT sample of 1,200 is required to detect the small rate difference in MI between PDT and VEGF inhibitor patients



**Fig. 1.** Results from Cox proportional hazards regression: cumulative survival for MI admission or death in patients treated with intravitreal injections of bevacizumab or ranibizumab and the community (models included age, sex, history of MI, and history of diabetes). Risk of MI for patients treated with VEGF inhibitors compared with the untreated community group, adjusted HR, 2.29 (95% CIs, 1.16–4.54; *P* = 0.02).

(0.8% vs. 1.9%), with 70% power. Consequently, our statistical comparisons for PDT analyses were underpowered. Likewise, there was insufficient power to detect differences between patients treated with bevacizumab and ranibizumab because of the few events in each group. However, our finding of no differences in thromboembolic events for patients treated with these drugs is consistent with recent findings from the CATT and IVAN studies.<sup>33</sup> Pooling of data across jurisdictions will be required to obtain a larger group for further analysis, and we are currently collaborating with national and international groups to address this.

We found that the risk of MI admission or death did not increase with the number of VEGF inhibitor injections received. Our data suggested that patients receiving multiple treatments did not differ from those receiving only one or two in terms of their age, sex, residential location, socioeconomic status, or diabetes history. Myocardial infarction admission did not always signal the end of VEGF inhibitor treatments, suggesting that this was not a simple survivor bias for all. Evidence of a dose–response relationship usually suggests a causal relationship<sup>34</sup>; however, other studies have reported that adverse effects from VEGF inhibitors are idiosyncratic rather than dose-related.<sup>35,36</sup>

We accessed all hospital and death records for the study participants but did not have details of medication use, family history, or lifestyle and behavioral factors that might affect the risk of MI, stroke, and GI bleeding for individual patients. Only serious episodes of GI bleeding and diabetes requiring hospitalization would have been identified, so it is likely we have underestimated their risk or prevalence, respectively.

The strength of our study was that it was a population-based, Phase-IV “real-world” study. We used the data that are highly representative of the Australian population<sup>27,37</sup> and had complete follow-up for admissions and death for MI, stroke, and GI bleeding within 12 months of the index treatment. The comparison groups were well matched for sex, socioeconomic status, residential location, and prior MI, and we were able to adjust for diabetes and age. Finally, we had access to treatment records for every patient receiving intravitreal VEGF inhibitors and PDT in WA over the study period.

## Conclusion

Given the expansive growth in VEGF inhibitor treatment for AMD and other eye conditions, the issue of increased MI risk is important. We found that the 12-month rate for MI after treatment with VEGF inhibitors was low but elevated compared with the community. It remains unclear whether the increased

risk to VEGF inhibitor patients is associated with AMD itself or its treatment with bevacizumab or ranibizumab. The seriousness of this adverse event warrants further investigation of the possible association between the use of VEGF inhibitors and MI, with pooling of data to increase statistical power.

**Key words:** adverse events, age-related macular degeneration, bevacizumab, choroidal neovascularization, postmarketing surveillance, ranibizumab.

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**Assessing the diagnostic validity of a blind register** *Clinical and Experimental Ophthalmology* 2011; 39(6):494-500.



## Original Article

## Assessing the diagnostic validity of a blind register

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## ABSTRACT

**Background:** To validate the accuracy of clinical ophthalmic information held on the West Australian blind register.

**Design:** Community-based cross-sectional study.

**Participants:** Legally blind or severely vision-impaired people were selected randomly from the Association for the Blind of Western Australia register.

**Methods:** Individuals were reviewed by one of two consultant ophthalmologists.

**Main Outcome Measures:** The positive predictive value (ppv), sensitivity and specificity for legal blindness status and diagnostic causes of vision loss were calculated using data extracted from the Association for the Blind of Western Australia blind register.

**Results:** 273 blind or near blind people were reviewed from the register total of 4271 individuals. There were more women (57%) than men, median age 81 years. For legal blindness status the ppv was 0.88 (95% confidence interval [CI] 0.82–0.92), sensitivity 0.75 (95% CI 0.74–0.84) and specificity 0.6 (95% CI 0.46–0.73). The ppv for the diagnostic causes of blindness were: age-related macular degeneration = 0.95 (95% CI 0.91–0.97), retinitis pigmentosa ppv = 1 (95% CI 0.81–1.0), diabetic retinopathy ppv = 0.9 (95% CI 0.57–0.99), optic neuropathies ppv = 0.77 (95% CI 0.51–0.92) and glaucoma ppv = 0.87 (95% CI 0.7–0.96). Forty individuals (15%) had treatable conditions contributing to their vision loss.

**Conclusions:** The blind register diagnoses and legal blindness status are of high accuracy. This information allows useful linkages to other databases for studies of blindness interactions. A regular updating mechanism would improve the future accuracy of this valuable regional asset. The presence of untreated cataract suggests that regular follow up and appropriate treatment may help optimize vision in blind patients.

**Key words:** blindness, blind register, positive predictive value, validation.

## INTRODUCTION

Our understanding, treatment and provision of support services for the vision-impaired and blind are enhanced by having an accurate clinical database or register of those affected. In Western Australia (WA), the Association for the Blind of Western Australia (ABWA) client database forms the blind register, and the aim of this study was to validate the clinical ophthalmic information described in this register.

Western Australia occupies a third of the Australian continent, and has about 10% (2.24 million) of the Australian population, most of whom reside in the Perth urban region (1.95 million). The WA demographics reflect those of the national population, with the indigenous population comprising 3% of the WA population, 78% are Caucasian, 18% are from South and East Asia and 1% are African or Hispanic in origin.<sup>1</sup>

Vision-impaired individuals were referred to ABWA for support and rehabilitation services by

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general practitioners, optometrists, ophthalmologists or by self-referral. At registration, clinical details supplied by an ophthalmologist or optometrist are recorded on the ABWA database. The patient will then be contacted by ABWA and reviewed in a low vision clinic by an optometrist or orthoptist who documents their functional vision. A weakness of this voluntary register is that it is incomplete. Despite this, as the sole service provider in this region of Australia, the ABWA holds the largest repository of data on the blind and vision-impaired.

In September 2009, the ABWA register had 4271 listed individuals. Of these, 1612 (38%) were recorded as being legally blind and were confirmed to be alive at the end of the study period (November 2009). This was made possible by linking data records of the WA state register of deaths with the study cohort. Only 17 (1%) of ABWA-registered legally blind people were recorded as being Aboriginal or Torres Strait Islanders.

## METHODS

Individuals were randomly selected from the ABWA register database. We selected all those who were deemed to be severely vision-impaired having a best corrected visual acuity (BCVA) LogMAR  $\geq 0.7$  (6/30 or worse) or who had  $<20^\circ$  diameter of visual field in their better eye. These individuals were invited to join the study. Invites were sent to the last known residential address recorded in the ABWA register.

Each person was subsequently contacted by telephone, by a single researcher (JC), who explained the study aims and objectives. Individuals who were interested and able to travel to a clinical appraisal received a complete ophthalmic review – performed by one of two consultant ophthalmologists (WM, NM) where the medical and ophthalmic history and examination results were recorded without reference to ABWA clinical records.

Legal blindness status was defined as having a BCVA of LogMAR  $>1$  or  $<10^\circ$  diameter of visual field, or a combination of both reduced visual acuity and field restriction, resulting in an equivalent level of vision loss, in the better eye. Individuals found to be not legally blind were termed near blind for the purposes of this study. Prioritized causes of vision loss as determined by the ophthalmologist, previous ophthalmic surgery, BCVA and field restriction were recorded for each eye separately. Demographic details, date of most recent ophthalmic appointment, and any reported comorbid conditions were recorded for each individual person. Clinical information from the review was recorded in a Microsoft Access database ver.2007.

The blind register recorded clinical information provided by optometrists and ophthalmologists. His-

torically, clinical information relating to the diagnoses and causes of vision loss were recorded for each person, rather than for individual eyes. Where more than one pathology was found to relate to loss of vision, the diagnoses were listed rather than ranked. The ABWA records were transposed into Microsoft Access relational tables for comparison with the findings of the clinical review assessment.

The positive predictive value (ppv) for legal blindness status and for each of the causes of blindness were calculated using person data rather than for separate eyes; that is, if the clinical review recorded glaucoma as the primary cause in one eye and age-related macular degeneration (AMD) in the contra lateral eye and the register recorded both glaucoma and AMD for this person, this would be considered to have a totally accurate record of diagnoses. But if the register showed only AMD for the same individual, then the diagnoses would be considered accurate for AMD and incomplete for glaucoma.

SPSS v17 (SPSS Inc., Chicago, Illinois, USA) and Stata v10 (StataCorp LP, Texas, USA) were used to analyse the data.

This study had Curtin University Human Research Ethics Committee approval and all participants gave written consent for the use of the de-identified collated data.

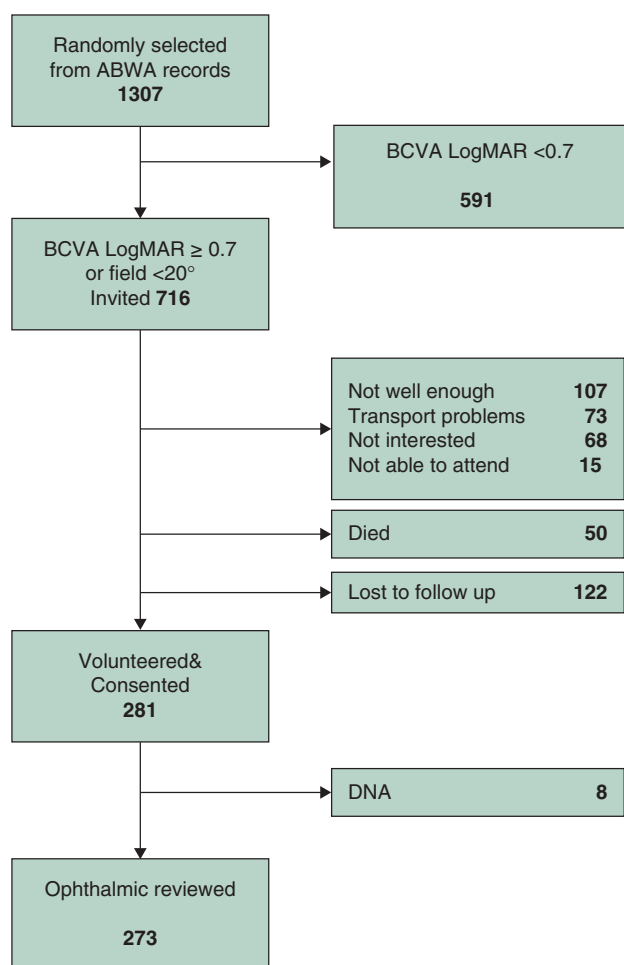
## RESULTS

From the ABWA register 1367 individuals were randomly selected, of which 716 had a BCVA LogMAR  $\geq 0.7$  (Fig. 1). Of those, 17% ( $n = 122$ ) had been lost to follow up, 50 (7%) had died since last contact, and 263 (37%) were either not well enough, not able to attend or not interested in attending the clinics.

We reviewed 273 severely vision-impaired or legally blind individuals which represented 12% of all the individuals listed on the register. The age and gender demographics of the cohort are shown in Table 1. There were more women ( $n = 155$ ) than men ( $n = 118$ ) and the median age was 81 (range 3–99) years.

### Legal blindness

We found that 217 (79%) of the 273 reviewed individuals met the criteria for legal blindness status having either a BCVA LogMAR  $>1$  or a retinal field restriction of  $<10^\circ$  or a combination of both a reduced visual acuity and field loss resulting in the same level of disability, in the better eye. However, 54 (20% of the total number reviewed) were not recorded on the register as being legally blind, and 22 others (8%) who were registered as legally blind



**Figure 1.** Flow chart of patient selection from the whole register of the Association for the Blind of Western Australia (ABWA) through to the review clinics. Registered clients were initially selected randomly, and then sub-selected for those having a best corrected visual acuity (BCVA) LogMAR  $\geq 0.7$  or visual field loss  $<20^\circ$  and finally invited to attend an ophthalmic review clinic.

were found to be near blind/vision-impaired at review. So the ppv of the register legal blindness categorization for the actual legal blindness status, as determined by the clinical review, was calculated as 0.88 (Table 2).

The age and gender demographics of the 56 near blind individuals (found to not be legally blind in the review clinics) did not differ significantly from those of the group who were confirmed as legally blind (Table 1).

Data collated from the review clinics found that most of the vision loss and blindness in this cohort was caused by AMD (65%). More eyes were affected by neovascular AMD (36.1%) than atrophic AMD (28.9%). Glaucoma was found in 14.6%, congenital retinal dystrophies including retinitis pigmentosa, Stargardt's, Ushers and others in 9.5%, optic atrophy

in 6.2%, other congenital conditions in 4% and diabetic retinopathy in 3.7%.

## Diagnoses

The ppv, sensitivity and specificity of each of the causes of blindness in this cohort are shown in Table 2. After the review of 546 eyes of 273 individuals we found that 26 individuals (9.4%) had conflicting variations in their diagnoses compared with the diagnoses recorded in the register. Fourteen of these were considered minor discrepancies being due mainly to missing, unavailable or unknown diagnoses in the register (Table 3).

**Age-related macular degeneration** was found to cause bilateral vision loss in 177 (65%) individuals at review. Seven of these people were found to have a primary diagnosis of AMD contributing to vision loss that was not included in their registered diagnoses. A total of 188 eyes were found to be affected by neovascular AMD and 159 by atrophic AMD. Of these 177 individuals, 133 (75%) were legally blind. The register listed 178 individuals with a diagnosis of AMD but eight people were not confirmed to have AMD at review giving a ppv of 0.95 (95% confidence interval [CI] 0.91–0.97).

**Glaucoma** had a ppv of 0.87 (95% CI 0.70–0.96). Of the 33 people registered with a diagnosis of glaucoma relating to their vision loss, four were not confirmed at review. The review clinics found 66 eyes with glaucoma contributing to vision loss in 40 individuals (26 bilateral, 14 unilateral). Eleven of these people (nine bilateral, two unilateral) were not listed as having glaucoma at all on the register.

**Retinal dystrophies** were relatively accurately recorded by the register (ppv = 0.92, 95% CI 0.71–0.98). This group included retinitis pigmentosa ( $n = 12$  individuals), Stargardt's disease ( $n = 6$ ), Ushers syndrome ( $n = 1$ ), rod-cone dystrophy ( $n = 1$ ), choroidal dystrophy ( $n = 1$ ) and macular dystrophy ( $n = 1$ ). All were bilaterally affected and all were legally blind. There were three additional individuals not registered with a retinal dystrophy but who were confirmed in the review clinics; as bull's eye maculopathy ( $n = 2$ ), and one case of Leber's congenital amaurosis. These had registered diagnoses of AMD  $\times 2$  and missing diagnostic information (respectively).

**Optic neuropathy** was diagnosed in 17 people (14 bilateral and three unilateral). Fourteen of these were registered as such by the ABWA. Additionally, four others on the register had this diagnosis, but were not confirmed at review. The ppv was 0.77 (95% CI 0.51–0.92).

**Diabetic retinopathy** was identified as the primary cause of vision loss in 10 people (20 eyes), seven were legally blind and three near blind. All

**Table 1.** Demographics (gender and age) of the study cohort separated into those who were legally blind or near blind on the register and those confirmed as legally blind or near blind in the review clinics

	Total	Review clinic legally blind		Review clinic near blind	
Registered legally blind ( <i>n</i> )	184	163		21	
Registered near blind ( <i>n</i> )	89	54		35	
		Male	Female	Male	Female
Registered legally blind ( <i>n</i> )	184	74	89	9	12
Mean age (years) (SD)		72 (20.0)	77 (16.6)	76 (13.3)	83 (10.2)
Median age (years)		79	82	82	84
Range (years)		8–94	6–98	50–88	61–95
Previous review, mean months (SD)		25 (33.1)	18 (19.5)	26 (25.6)	13 (12.8)
Registered near blind ( <i>n</i> )	89	19	35	16	19
Mean age (years) (SD)		61 (33.8)	74 (22.3)	66 (27.1)	71 (26.1)
Median age (years)		80	81	79	81
Range (years)		3–99	5–97	5–89	7–89
Previous review, mean months (SD)		29 (29.4)	22 (20.4)*	11 (14.9)	9 (8.3)*
Total ( <i>n</i> )	273				

SD, standard deviation. \*Independent *t*-test significant difference  $P < 0.05$ .

were accurately registered by the ABWA. One additional individual registered with diabetic retinopathy was not confirmed at review. For that patient, bilateral central retinal vein occlusion was the cause of the vision loss. The ppv was 0.90 (95% CI 0.57–0.99).

**Retinal vascular occlusions** were found in eight patients (11 eyes, 10 central retinal vein occlusions and one retinal artery occlusion). Five people were legally blind and three near blind. Five of these eight people were registered as having a retinal vascular occlusion. A further four people were registered with vascular occlusions but these were not confirmed at review. The ppv was 0.55 (95% CI 0.22–0.84).

Forty (15%) people were found to have a treatable condition which could lead to an improvement in their vision. These included 54 cataracts in 29 individuals, eight posterior capsular opacities in seven individuals, two pterygia and two people with reactivation retinal haemorrhaging which may respond to anti-vascular endothelial growth factor treatments.

There was a significant difference in the mean length of time since the last visit to an ophthalmologist between men (24.1 months, SD 32.3) and women (17.4 months, SD 18.5) (mean difference = 6.6, 95% CI 0.3–12.9,  $P = 0.04$ ) and also between people who were legally blind (22.4 months, SD 27.6) and those who were near blind (13.3 months, SD 15.8) (mean difference = 9.1, 95% CI 1.4–16.8,  $P = 0.02$ ) (Table 1).

Most of this cohort of severely vision-impaired and legally blind people had at least one self-reported comorbid condition ( $n = 214$ , 78%), with almost half (46%) having two or more additional

health issues. The most commonly (35%) reported comorbidity was hypertension.

## DISCUSSION

The legal blindness status recorded on the WA blind register was found to be relatively precise, making the register a useful resource for further linked health-care studies. The review clinics identified an additional 54 individuals (20%) who would also satisfy the criteria for legal blindness but who were registered only as vision-impaired. Other studies<sup>2,3</sup> have found that up to 33% of eligible legal blind individuals were not registered appropriately for support and rehabilitation.

The sensitivity of the register was moderately good (0.75, 95% CI 0.74–0.84) when recording legal blind status and the specificity was modest (0.6, 95% CI 0.46–0.73). These results may be explained by the fact that the ABWA register under-records legal blindness. This happens when individuals are initially registered as vision-impaired but who progress to legal blindness at a later date. The progression to legal blindness may not always be communicated to the ABWA, leading to delays in data revision and a reduction in the specificity of the register. A system for regularly updating the register would greatly improve the quality of the data and the research outcomes derived from them.

Conversely we found that 8% of individuals who were registered as legally blind were near blind or partially sighted on the day of assessment. There is a recognized test-retest variability in determining visual acuity of  $\pm 0.18$  (in terms of 95% ranges), so that those individuals with a registered visual acuity



**Table 2.** Positive predictive value (ppv) (probability of this status or diagnosis being present), negative predictive value (npv) (probability of not having the condition or diagnosis), sensitivity and specificity for legal blindness status and diagnostic causes of vision loss as recorded on the blind register compared with the status and diagnosis found in the review clinic

	True pos		True neg		False pos		False neg		ppv		(95% CI)		npv		(95% CI)		Sensitivity		(95% CI)		Specificity		(95% CI)	
	a	b	c	d	a/a + c	b/b + d	a/a + c	b/b + d	a/a + c	b/b + d	a/a + c	b/b + d	a/a + c	b/b + d	a/a + c	b/b + d	a/a + c	b/b + d	a/a + c	b/b + d	a/a + c	b/b + c	a/a + c	b/b + c
	Reg+	Reg-	Reg+	Reg-	Review+	Review-	Reg+	Reg-	Review+	Review-	Reg+	Reg-	Review+	Review-	Reg+	Reg-	Review+	Review-	Reg+	Reg-	Review+	Review-	Reg+	Reg-
Legal blindness	163	34	22	54	0.88	0.39	0.88	0.39	0.88	0.39	(0.82–0.92)	(0.29–0.49)	0.75	0.60	(0.69–0.81)	(0.46–0.73)								
AMD	170	88	8	7	0.95	0.93	0.95	0.93	0.95	0.93	(0.91–0.97)	(0.85–0.97)	0.96	0.91	(0.91–0.98)	(0.83–0.96)								
Glaucoma	29	229	4	11	0.87	0.95	0.87	0.95	0.87	0.95	(0.7–0.96)	(0.91–0.97)	0.72	0.98	(0.55–0.84)	(0.95–0.99)								
Congenital retinal dystrophies	22	246	2	3	0.92	0.98	0.92	0.98	0.92	0.98	(0.71–0.98)	(0.96–0.99)	0.88	0.99	(0.67–0.96)	(0.97–0.99)								
Optic neuropathy	14	252	4	3	0.77	0.99	0.77	0.99	0.77	0.99	(0.51–0.92)	(0.96–0.99)	0.82	0.98	(0.55–0.95)	(0.95–0.99)								
Diabetic retinopathy	10	262	1	0	0.90	1.0	0.90	1.0	0.90	1.0	(0.57–0.99)	(0.98–1.0)	1.00	0.99	(0.65–1.0)	(0.97–0.99)								
Retinal occlusion	5	261	4	3	0.55	0.98	0.55	0.98	0.55	0.98	(0.22–0.84)	(0.96–0.99)	0.62	0.98	(0.25–0.89)	(0.95–0.99)								

AMD, age-related macular degeneration; CI, confidence interval; Reg+, registered as legally blind or with diagnosis; Reg-, registered as vision-impaired or not having diagnosis; Review+, review clinic confirmed; Review-, review clinic did not confirm.

of close to LogMAR = 1.0 could, by chance, be found over or under the legal blindness cut-off mark on the day of review.<sup>4</sup> Additionally, Snellen charts are widely used by those submitting the registration forms to the ABWA, and this could also lead to greater variability in the recorded visual acuity measurement in the register data.<sup>5</sup>

A UK study found that after review of blind registration forms (BD8 forms), 6% of those recorded as legally blind were vision-impaired.<sup>6</sup> In Scotland, 17% of patients were re-categorized after review of registration forms from blind to partially sighted<sup>7</sup> and in the West Midlands UK, 34% were found to be inappropriately registered as legally blind after a retrospective chart review.<sup>3</sup>

Patients volunteered to attend these review clinics and therefore this study cohort may not truly be representative of the overall WA population of severely vision-impaired and blind people. However, we found the proportions of each of the primary causes of vision loss in this cohort were broadly similar to those of the group who did not attend and also similar to those previously reported for WA (Fig. 2).<sup>8</sup>

Western Australia is a geographically vast region, so this sample cohort may also have underrepresented the number of blind people with debilitating comorbid conditions, especially conditions that make travelling difficult or impossible. These conditions will have a greater impact on people living in rural and remote regions of WA.

We found retinal dystrophies and AMD were the most accurately diagnosed and registered causes of blindness. On the other hand, retinal vascular occlusions and glaucoma were the diagnoses that were possibly overlooked, misdiagnosed or inaccurately recorded at registration. The diagnosis of retinal vascular occlusion may not necessarily be evident years after the event, and may not have been detectable at review, in all cases. The relative contribution of glaucoma to the overall blindness may be difficult to assess, particularly in the presence of other problems such as AMD.

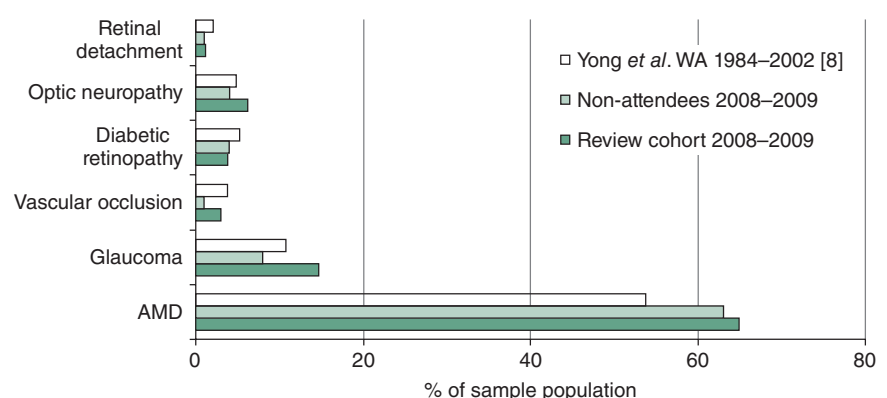
Three Aboriginal persons were randomly selected and reviewed in the study clinics. They were all found to be legally blind. Taylor *et al.*<sup>9</sup> have recently estimated that up to 1.9% of Aboriginal persons were likely to be legally blind, which suggests in WA, about 639 of 71 000.<sup>10</sup> Clearly, very few of these are currently registered with ABWA for assistance ( $n = 17$ ), highlighting an area of great need. The issue of how to identify and provide appropriate services for blind and vision-impaired Aboriginal persons requires urgent attention.

An accurate clinical database of the changing patterns of the causes and extent of blindness in the community, will allow for better planning, treatment

**Table 3.** Summary of variations found in the diagnoses in the review clinic (two left hand columns for right and left eyes, respectively), compared to the diagnoses on the register (two right hand columns for first and second listed diagnoses, respectively)

	Review clinic	Review clinic	ABWA	ABWA
	Right primary diagnosis	Left primary diagnosis	Diagnosis 1	Diagnosis 2
<i>Major variations</i>				
1	Macular dystrophy	Macular dystrophy	Lebers optic atrophy	Lebers optic atrophy
2	Retinal detachment	AMD	AMD	Br. retinal vein occl.
3	AMD	Trauma	AMD	Br. retinal vein occl.
4	AMD	AMD	Stargardts	Stargardts
5	AMD	AMD	Stargardts	Cataract
6	Homonymous hemianopia	Homonymous hemianopia	AMD	Cataract
7	Myopic macular degen.	Myopic macular degen.	AMD	Optic neuropathy
8	Retinal vein occlusion	Retinal vein occlusion	Diabetic retinopathy	Optic neuropathy
9	Choroideraemia	Choroideraemia	Glaucoma	Cataract
10	Amblyopia	Endog. endophthalmitis	Glaucoma	n/a
11	Congenital falciform folds	Congenital falciform folds	Glaucoma	Cataract
12	Hysterical blindness	Hysterical blindness	Glaucoma	n/a
<i>Minor variations</i>				
13	AMD	Corneal decompensation	AMD	n/a
14	AMD	Retinal detachment	AMD	n/a
15	AMD	AMD	IOL	n/a
16	AMD	AMD	n/a	n/a
17	Glaucoma	AMD	AMD	n/a
18	AMD	Glaucoma	Glaucoma	n/a
19	Bull's eye maculopathy	Bull's eye maculopathy	AMD	n/a
20	Failed PK	Failed PK	Keratitis	Corneal opacity
21	Macula oedema/ epiretinal membrane	Trauma	Macular degeneration	Trauma
22	Optic neuropathy	No vision loss	Tumour	n/a
23	Optic neuropathy	Optic neuropathy	n/a	n/a
24	Lebers congen. amaurosis	Lebers congen. amaurosis	n/a	n/a
25	Bull's eye maculopathy	Bull's eye maculopathy	AMD	Cataract
26	Myopic macular degen.	Glaucoma	Glaucoma	Cataract

Minor discrepancies were generally cases where data was missing, unavailable or unknown. Major differences were judged, by the ophthalmologists, to be clinical errors. ABWA, Association for the Blind of Western Australia; AMD, age-related macular degeneration; IOL, intraocular lens; n/a, not available; PK, penetrating keratoplasty.

**Figure 2.** Comparative frequencies of the major causes of blindness in this study cohort, in those who did not attend and in a previous Western Australian (WA) blind register incidence report.<sup>8</sup> AMD, age-related macular degeneration.

and delivery of health services for the severely vision-impaired.

By monitoring changes in disease incidence and prevalence, we can better understand the impact brought about by targeted programmes or treatments for blinding eye disease.

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# Prevalence of blindness in Western Australia: a population study using capture and recapture techniques

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## ABSTRACT

**Aim** To determine the prevalence of blinding eye disease in Western Australia using a capture and recapture methodology.

**Methods** Three independent lists of residents of Western Australia who were also legally blind were collated during the capture periods in 2008–9. The first list was obtained from the state-wide blind register. A second list comprised patients routinely attending hospital outpatient eye clinics over a 6-month period in 2008. The third list was patients attending ophthalmologists' routine clinical appointments over a 6-week period in 2009. Lists were compared to identify those individuals who were captured on each list and those who were recaptured by subsequent lists. Log-linear models were used to calculate the best fit and estimate the prevalence of blindness in the Western Australian population and extrapolated to a national prevalence of blindness in Australia.

**Results** 1771 legally blind people were identified on three separate lists. The best estimate of the prevalence of blindness in Western Australia was 3384 (95% CI 2947 to 3983) or 0.15% of the population of 2.25 million. Extrapolating to the national population (21.87 million) gave a prevalence of legal blindness of approximately 32 892 or 0.15%.

**Conclusion** Capture–recapture techniques can be used to determine the prevalence of blindness in whole populations. The calculated prevalence of blindness suggested that up to 30% of legally blind people may not be receiving available financial support and up to 60% were not accessing rehabilitation services.

more recently been used and validated by epidemiologists to estimate the prevalence of medical conditions such as postoperative joint infections, brain injury, diabetes and pertussis in infants.<sup>7–11</sup> The method utilises overlapping incomplete lists of affected individuals collated during repeated 'capture' exercises to estimate the size of the unsampled portion of the population. It also assess the degree of undercounting.

Our aim was to use capture–recapture methodology to determine the true prevalence of blindness in Western Australia. The results will enable us to improve the referral process by which people who are vision impaired are directed to support service providers, to monitor interventions and to predict future healthcare needs and costs.

## METHODS

Legal blindness in Australia is defined as having a best corrected visual acuity of LogMAR greater than 1 or a visual field restriction of less than 10° from central fixation or a combination of both reduced visual acuity and field loss resulting in the equivalent level of disability in the better eye.

In this study three separate 'capture' lists of people who were legally blind and resident in Western Australia (lists A, B and C), were collated over an 18-month period between April 2008 and September 2009. Western Australia has four tertiary-level hospitals including a paediatric hospital, each with public ophthalmology clinics, which contributed cases to the study. Both urban and rural-based consultant ophthalmologists, general practitioners and an optometrist enrolled patients in the study. Optometrists or ophthalmic nurses determined the level of vision loss. The diagnostic cause of vision loss and legal blindness status were determined by consultant ophthalmologists using full clinical notes, in all cases.

This study was approved by the human research ethics committees of Curtin University and participating hospitals.

List A was derived from the blind register held by the Association for the Blind of Western Australia. This recorded all individuals who were vision impaired or legally blind who were either self-referred, or referred by ophthalmologists, optometrists or healthcare providers from anywhere within the state. It is a voluntary system of referral and has high diagnostic accuracy with a positive predictive value of 0.88 for legal blindness status.<sup>12</sup>

The prevalence of blindness is a fundamental measure required effectively to target intervention programmes and to provide hard data against which progress can be evaluated. Most information on the prevalence of blindness is derived from blind registers or sampling surveys.<sup>1–2</sup> The conventional approach to creating blind registers is by voluntary referrals from general practitioners and ophthalmologists. Reports have shown that underreporting of eligible patients was a significant problem particularly when there was no evaluation of the degree of ascertainment.<sup>3–4</sup> Alternative methods for determining the prevalence of blindness have required sampling surveys of communities or complete population census data collection.<sup>5–6</sup>

Capture–recapture techniques were initially developed to estimate animal populations but have

List B was collated over the 6-month period April to September 2008. It consisted of patients who were legally blind attending routine appointments at either public hospital outpatient eye clinics or selected consultant ophthalmologists' clinics or who were assessed by an optometrist.

Patients were not enrolled within a 7-day postoperative period. There were no age limits on being listed as legally blind. Listed patients gave consent for their identifiers (first name, middle name, last name, gender and date of birth) to be utilised for the specific purposes of this study. Patients were enlisted using standardised forms to record the level and cause of vision loss.

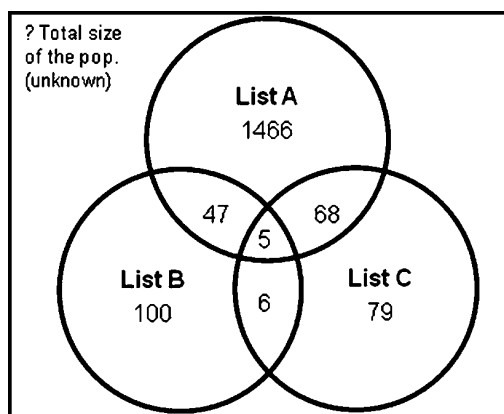
The third data list (C) was collected over a 6-week period August–September 2009. Eligible patients comprised those who were legally blind and attending either a tertiary hospital outpatient eye clinic or a consultant ophthalmologist's rooms or selected general medical practitioners' clinics. The methodology, selection and inclusion criteria were identical for this list as those for list B and were confirmed by ophthalmologists in all cases.

Deterministic unique matching with clerical review between lists (A, B and C) was achieved using available identifier fields: date of birth, gender, first and last names. All legally blind individuals listed on the blind register (list A) at 30 September 2009, with residential post codes within Western Australian state boundaries (post codes 6000–6999) were selected. Individuals with a matched identity on the state register of deaths, with a date of death before the end of the collection period were excluded. This facility was made possible by the Western Australian data linkage unit and permitted the accurate calculation of outmigration due to deaths in the blind register population.

Following the identification of the total number of individuals contained in the three lists and the matches identified between lists, the data were classified into seven cells of a three-way contingency table. The table has eight cells ( $2^3$ ) with the eighth cell corresponding to blind individuals who were absent from all three lists. The data are illustrated in a Venn diagram (figure 1) and in an incomplete contingency table (table 1). Incomplete contingency tables were used to estimate the number of individuals in the missing cell of the table using log-linear modelling.<sup>13 14</sup>

### Log-linear modelling

The logarithm of the count in each cell of the table was modelled as a linear function of terms indicating the presence or



**Figure 1** Venn diagram showing the distribution of 1771 individuals who were legally blind, to illustrate the overlap between the number of people who were blind and identified on each of the three lists: A, blind register; B, individuals attending routine hospital outpatient eye clinics 2008; and C, individuals attending ophthalmologist or general practitioner appointments 2009.

**Table 1** Contingency table showing the distribution of 1771 individuals who were legally blind, between three lists

	Recapture (C) present		Recapture (C) absent	
	Capture (B) present	Capture (B) absent	Capture (B) present	Capture (B) absent
Blind register (A) present	5	68	47	1466
Blind register (A) absent	6	79	100	—

A, blind register; B, individuals attending routine hospital outpatient eye clinics 2008; and C, individuals attending ophthalmologist or general practitioner clinical appointments 2009.

absence on each dimension (list). Pair-wise dependence of lists can be modelled as interaction terms between the relevant lists.

Explicitly: the log-linear model may be expressed using the following notation (following Chao *et al*):<sup>14</sup>

$$\text{Log}(M_{a,b,c}) = u + u_{(a)} + u_{(b)} + u_{(c)} + u_{(a,b)} + u_{(a,c)} + u_{(b,c)}$$

Where  $M_{a,b,c}$  represents the expected number of people identified in the combination of lists given by the indices a, b and c; as the 'intercept' term in the linear model,  $u$  represents the logarithm of the number not captured; other terms in the model represent the influence of relevant list membership (or 'joint' membership for interaction terms) on the expected number in that list (or combination of lists). It must be assumed that no three-way interaction term is present, so that the final (unknown) cell can be determined from the estimates of the main effects and two-way interaction terms in the model. Seven models were fitted to the data: one with no interactions (indicating that memberships of lists were independent of each other), three models with one two-way interaction term, and three models with two two-way interaction terms. Models fitted are shown in supplementary table 2, available online only.

The simplest model (least number of estimated parameters) in which the deviance indicated an adequate fit ( $p > 0.05$ ,  $\chi^2$  statistic with the appropriate degrees of freedom) was selected as the best model. The purpose of fitting the model was to estimate the number of people who were not captured in any of the lists. This number was estimated for each model, and was added to the number of people who were present in at least one list, to obtain an estimate of the total population of blind people. The 95% CI for the number not captured provide an indication of the reliability of the final population prevalence estimate.

Dependencies between source lists appear as statistically significant interaction terms in the log-linear model. The interaction term in the model attempts to correct for any dependence, and results in a model that fits the observed data better. The influence of this dependence on the estimate of people not listed is difficult to predict. However, more confidence can be placed in estimates that are derived from models that describe the data well. The interaction terms were included when they provide a significant improvement to the goodness of fit of the model. The model coefficients were estimated using the 'Genmod' procedure, SAS software program, version 9.1. Other analyses were carried out using PASW Statistics v18, (Microsoft).

Previous studies of the prevalence of blindness in Australia have been age restricted (50 years or more) in which blindness is more frequent.<sup>5 15</sup> To compare the estimate of this study with previous estimates we recalculated the capture–recapture prevalence estimates, using the same matrices and models, after selecting only those people who were blind and aged 50 years or more, in each of the three collated lists.

All Australian adults who are legally blind are eligible for financial support in the form of a government pension. For the

## Global issues

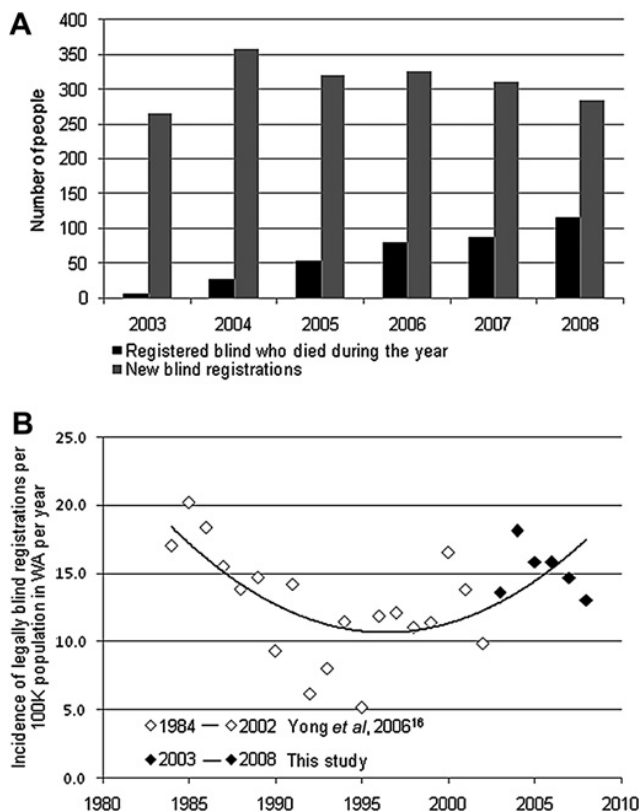
purposes of validation and comparison, we compared the estimated prevalence of blindness with the total number of blind pension recipients in the state, during the periods of data collection for this study. These de-identified data were made available by the Australian federal government offices of the Department of Families and Housing, Community Services and Indigenous Affairs.

## RESULTS

This study identified 1771 individuals resident in Western Australia who were legally blind. There were 721 male and 1050 female individuals ranging in age from 1 year to 106 years at the end of the data collection period in 2009.

The blind register (list A) contained 1586 individuals who were confirmed as being alive and resident in the state of Western Australia. Eleven people on the blind register had recorded dates of death that could not be confirmed by the state register of deaths, and all were included in the analysis. Eight people from list B and one from list C died before the end of the study period (October 2009), and were not included in the final analysis. After clerical checking, 46 people on the blind register were excluded as they had no known residential post code in Western Australia (6000–6999) and were lost to follow-up.

The mean incidence of people who were legally blind added to the blind register over the previous 5 years (2004–8) was 320 per year or a cumulative incidence of 16 per 100 000 population per year (figure 2A). The combined incidence of legally blind over the previous 24 years is shown in figure 2B.<sup>16</sup>



**Figure 2** (A) Incidence in Western Australia (WA) of individuals who were registered as legally blind each year and the number of deaths in this population 2003–8. (B) Incidence of individuals who were legally blind registered annually in Western Australia per 100 000 population over 24 years. Data from a previous study, Yong *et al*<sup>16</sup> and from this study.

The distribution of people across the three ‘capture’ lists is shown in figure 1. List B had 158 people who were blind, of which 100 were not present on either of the other lists (A and C). Thirty-seven were nursing home residents and of these, five were matched to people on list A. List C contained 158 people who were blind, of whom 79 were not present on either list A or list B. No nursing home residents were identified on list C. Five people were present on all three lists and six were present on both list B and list C.

Using log-linear modelling the simplest model, with no interactions between the three lists, led to a poor fit with the data ( $p=0.021$ ). The model with one interaction term (3) showed the best fit (deviance 2.63,  $p=0.268$ ). The calculated estimate of the ‘uncaptured’ portion of the blind population was 1613. Together with the previous 1771 ‘captured’, this provided a best estimate of the total state population of legally blind in 2009 as 3384 (95% CI 2947 to 3983) (see supplementary table 3, available online only).

An age restricted (50 years or more) population prevalence estimate was also calculated in the same way (see supplementary figure 3, available online only). Using the same model (3) with a single interaction and the best fit ( $p=0.142$ ), we obtained an estimate of the number of people who were blind to be 2859 (95% CI 2470 to 3408) or 0.43% of the state population aged 50 years or more ( $n=666\,009$ )<sup>17</sup> (see supplementary table 4, available online only).

Extrapolating these results to a national level, the prevalence of legal blindness in Australia in 2009 was 32 892 (95% CI 28 645 to 38 715) equivalent to 0.15% of the national population of 21.9 million. The age restricted ( $\geq 50$  years) prevalence of blindness was 0.4% (95% CI 0.37% to 0.51%).

The estimated prevalence of people who were blind in Western Australia exceeded both the total number of recipients of the blind pension ( $n=2244$ ) and the number registered for support with the Association for the Blind of Western Australia (see supplementary figure 4, available online only).

## DISCUSSION

This is the first study that we are aware of to use capture and recapture mathematics to calculate the prevalence of blindness in a whole population. We estimated that 3384 (95% CI 2947 to 3983) or 0.15% of the Western Australia population of 2.25 million were legally blind at the end of September 2009. This is higher than either the number receiving the government blind pension or those registered for support from the Association for the Blind of Western Australia.

Comparing this prevalence estimate with previous cross-sectional Australian studies, we found that the results were remarkably similar. Both the Melbourne Visual Impairment Project<sup>18</sup> and the Blue Mountains Eye Study<sup>5</sup> reported a prevalence of legal blindness of 0.5% in the population aged 50 years or more. This suggests that the capture–recapture technique is a valid and highly cost-effective method compared with traditional cross-sectional, population-based surveys for determining disease prevalence.

The strengths of this study are the moderately stable and relatively isolated population. It was recently shown that the Western Australian population is representative of the Australian population as a whole.<sup>19</sup> Therefore, data from this study can reasonably be extrapolated to the national population of Australia. All individuals who were legally blind were included in this estimate, with no age restrictions. A prevalence estimate has been obtained from a disparate and low prevalence population

that is comparable to previous published estimates derived from large population sampling surveys.

The study was limited by two of the four assumptions of capture–recapture estimations: equal capture probabilities and a closed population (no births, deaths or migration). It is commonly accepted that this latter assumption can rarely be fulfilled in human applications.<sup>20</sup> The provision of medical services in rural Western Australia (geographical area 2.65 million km<sup>2</sup>) is limited, and as a result data collection from the very remote regions of the state was low, but not zero. In addition, people living in residential nursing care facilities, although not specifically excluded, were less likely to attend hospital or other clinical appointments and therefore the probability of being ‘captured’ was not equal when compared with others in the community. As remotely isolated people and nursing home residents were previously found to have a higher prevalence of blindness than the general population<sup>6 21–23</sup> this would result in an underestimation of the true blind population.

These results have shown that relevant government and community agencies are unaware of many people who are legally blind. While it is possible that people who are blind may choose not to claim income support, may be financially independent or may not wish to be identified as legally blind, these results suggest that there may be up to 35% more people who are legally blind and eligible for financial support than are currently in receipt of a blind pension in Western Australia. We also found that only one third of individuals who are legally blind have ever been referred to or have visited the only provider of support services in the state, leaving 60% of individuals without rehabilitation support. Understanding the full extent of the burden of blindness will help to improve the targeting of appropriate rehabilitation programmes with special emphasis on psychological issues, increasing mobility and social connectivity.

This capture–recapture study has shown that it is a relatively efficient and cost-effective method for the accurate estimation of the prevalence of legal blindness.

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**Competing interests** None.

**Ethics approval** This study was approved by the human research ethics committees of Curtin University and participating hospitals.

**Contributors** The following are all members of the Eye and Vision Epidemiology Research (EVER) group and this project was part of the Epidemiology of Blinding Eye Disease Study (EBEDS). Author contributions to this paper: JC: Overall study co-ordination. Responsible for patient contact and clinic surveys. Responsible for data entry, data base security and validation checking. Carried out data analysis. Drafted, formatted and critically revised manuscript for publication. WHM: Clinical consultant ophthalmologist. Substantial contribution to conception of study design and clinical support for the project. Carried out clinical assessments of patients. Critically reviewed the manuscript providing important intellectual content. NM: Clinical consultant ophthalmologist. Substantial contribution to conception of study design and clinical support for the project. Carried out clinical assessments of patients. Critically reviewed

the manuscript providing important intellectual content. GL: Clinical consultant paediatric ophthalmologist. Substantial clinical support for the project. Critically reviewed the manuscript providing important intellectual content. RP: Biostatistician, providing advice and analysis on the capture–recapture methodology. AM: Computer programmer with responsibility for data extraction and data management. AC: Clinician and ophthalmic registrar who assisted with patient assessments and statistical advice. JN: Ophthalmic registrar who assisted with patient assessments. MC: Chief executive officer of the Association for the Blind of Western Australia (ABWA). Data custodian of ABWA client information. JS: Chief investigator with overall responsibility for project management. Critically reviewed the manuscript.

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## Original Article

# Hospitalization rates of children who are blind

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### ABSTRACT

**Background:** To evaluate the impact of blindness on hospitalization rates of children.

**Design:** Matched cohort study.

**Participants:** Children confirmed as legally blind (2003–2009), age- and gender-matched to control cohort of normally sighted children from the state register of births.

**Methods:** The rates and reasons for admission to hospital were compared using hospital morbidity records. The association of blindness with rates of admission and length of stay in hospital, 2003–2010, were estimated using multivariate negative binomial regression models.

**Main Outcome Measures:** Descriptive statistics, incident rate ratios, and predicted means for hospital separations and length of stay.

**Results:** Fifty-nine blind and 59 control children had a combined total of 107 separations accounting for 237 bed days in hospital after the index date of legal blindness. The median age at the index date was 8 years. Over 90% of separations and 92% of bed days were incurred by 22 blind children. Blind children had four (95% confidence interval 1.9–9.3) times more hospital separations and stayed in hospital six (95% confidence interval 1.9–17.5) times longer

than the control cohort children. There were more than 40 times as many comorbidities recorded by the blind children ( $n = 201$ ) compared with the control children ( $n = 5$ ). A third of the blind children were hospitalized for respiratory conditions.

**Conclusions:** Children who are born or become blind in childhood have more and longer periods in hospital than sighted children likely because of complex comorbid health problems. There was a disproportionate incidence of comorbid respiratory diseases in the blind children.

**Key words:** blind, children, hospitalization, respiratory.

### INTRODUCTION

Very little information exists on the health and well-being of children who become blind during childhood. Although there are data on the incidence and prevalence of different types of childhood blindness or vision loss,<sup>1–5</sup> there is no information on the health outcomes, hospitalization characteristics or comorbidities of children who become blind.

Blindness in the general community has a low prevalence (0.15%) and 0.02% in those aged less than 18 years.<sup>6,7</sup> Childhood blindness carries a high financial cost for the community as well as a high individual cost<sup>8</sup> that impacts, in particular, normal motor, language and social development, all compounded when the child enters the education system.<sup>9</sup>

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This matched cohort study examined the extent of hospital utilization by children who were legally blind during the period from 2003 to 2010. We compared the number of hospital separations and bed days attributed to the children who were blind and compared with a cohort of normally sighted children taking into account the various causes of vision loss, socioeconomic status and residential remoteness.

## METHODS

Blind children were identified from the voluntary register of the Association for the Blind of Western Australia and from paediatric ophthalmologists' clinics. The index date for the blind children was the date of first confirmation or registration as legally blind that occurred between May 2003 and September 2009. Legal blindness was confirmed in all cases by a specialist ophthalmologist. Blindness was defined as having a best-corrected visual acuity of logMAR >1 or <10° diameter of visual field, or a combination of both reduced visual acuity and field restriction, resulting in an equivalent level of vision loss in the better eye. Children whose clinical features were consistent with blindness (could not fix or follow light), but whose acuity could not be measured were also included. The blind register contained demographic details and previously validated clinical data on the causes and extent of vision loss.<sup>10</sup>

The children who were blind were age- and gender-matched in a 1:1 ratio with normally sighted control children from the state register of births. All hospital morbidity records from the earliest hospital admission through to 2010 for both the blind and sighted children were de-identified and collated. Each control child was attributed the same 'index date' as their blind-matched child to ensure an equitable length of follow up.

The data were analysed to compare the hospital separation rates, the number of bed days occupied, the diagnoses at separation and comorbidities that occurred after the index date. The number of separations post-index date was determined after excluding interhospital transfers. The length of stay (LOS) (the number of bed days) was defined as the separation date minus the admission date plus one. An Index of Relative Socioeconomic Disadvantage was assigned to each child based on residential address at the time of last hospital separation. This rating was based on aggregated household and individual attributes within the Australian Bureau of Statistics collector districts using 2006 census data. The Index of Relative Socioeconomic Disadvantage was used to divide the population into quartiles of disadvantage (1 most disadvantaged to 4 least disadvantaged).<sup>11</sup> The Accessibility and Remoteness Index of Australia

(ARIA+) was used to describe geographical accessibility at the time of hospital separation. ARIA+ measures access in terms of physical distance from services and is divided in to four broad levels of remoteness: major cities, inner regional, outer regional, remote and very remote regions of Australia.<sup>12</sup> ARIA+ categories were assigned to cases using the Australian Bureau of Statistics collector districts of the residential address at the time of last hospital separation.

The matching, linkage and extraction of state-wide administrative health records were carried out by the West Australian Data Linkage System. International Statistical Classification of Diseases and Related Health Problems, 10th revision, Australian Modification codes were used to identify primary and comorbid diagnoses associated with each hospital separation. Significance of association between rates of separation and LOS, and categorical factors were determined by chi-squared tests or by comparison of means for continuous variables using *t*-tests, with the level of significance set at 0.05. Negative binomial regression analysis was carried out to estimate the mean number of hospital separations and LOS after adjusting for blind status, gender, socioeconomic status, remoteness index and cause of blindness where appropriate. A purposeful backward stepwise selection of variables was performed to generate the most parsimonious regression models. Analysis was carried out using IBM PASW v18 (IBM Corporation, Armonk, NY, USA) and Stata v12 (StataCorp LP, College Station, TX, USA).

This study was approved by Curtin University Human Research Ethics Committee and by the Department of Health of Western Australia, Human Research Ethics Committee. We certify that all applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during this research.

## RESULTS

The matched cohort consisted of 59 legally blind children and 59 age- and gender-matched normally sighted control children. None of the control children appeared on the blind register or had any hospital primary diagnosis or comorbidity coding for blindness or ophthalmic-related problems and were presumed to be normally sighted. The median age at the index date of legal blindness was 8.2 years (standard deviation [SD]  $\pm$  4.2, range 0.2–16 years). Of the 59 children who were blind (54% male), 22 (37%) had at least one hospital stay after the index date of blindness (range 1–19) compared with 9 (15%) of the control children (range 1–2). Two blind children (14%) had a comorbidity code (H54.0) specifically mentioning their blind status. The characteristics,

**Table 1.** Demographics, hospital separation and bed days of the matched cohorts of blind and control children after the index date

	Controls	Blind	Total	<i>P</i> value
Gender (%)				
Male	32 (54)	32 (54)	64	1.0
Female	27 (46)	27 (46)	54	
Children with hospital admission (%)				
Yes	9 (15)	22 (37)	31	0.007
No	50 (85)	37 (63)	87	
Hospital admissions (%)	10 (9)	97 (91)	107	–
Bed days in hospital (%)	19 (8)	218 (92)	237	–
Admission type (%)				
Emergency	2 (20)	36 (37)	38	0.3
Elective	8 (80)	61 (63)	69	
Comorbidities				
Admissions with comorbidities ( <i>n</i> )	1 (6)	72 (201)	73	–
Admissions with no comorbidities ( <i>n</i> )	9	25	34	–
Legally blind and registered (%)				
Yes	0	50 (85)	–	–
No	59 (100)	9 (15)	–	–

–, not available.

number of separations and days spent in hospital for the blind and control cohorts are shown in Table 1.

### Cause of blindness

Retinal pathologies were the most common cause of blindness affecting 26 (44%) blind children (Table 2). Five children were blind, but the cause of vision loss was not sufficiently specified to classify them (e.g. Marfans syndrome-related). All conditions causing blindness in this cohort had a bilateral impact on vision resulting in legal blindness.

The mean age at the index date was not significantly different for children with either optic nerve damage ( $n = 14$ , mean age 9.8 years), retinal pathologies ( $n = 26$ , mean age 9.0 years) or cortical blindness ( $n = 4$ , mean age 6.2 years). However, children with blindness as a consequence of developmental abnormalities were significantly younger at the index date of blindness ( $n = 8$ , mean age 4.9 years, SD  $\pm 3.3$  years) than children with either retinal pathologies ( $t$ -test  $P = 0.01$ , 95% confidence interval [CI] 1.0–7.3) or optic nerve blindness ( $P = 0.01$ , 95% CI 1.5–8.4). The mean age at the index date was the same for males (8.1 years) and females (8.4 years) ( $P = 0.70$ ).

The cause of blindness in the children without hospital separations ( $n = 15$ ) were broadly similar to those of children with hospital separations, although they were significantly older (mean 10.9 years, SD 4.0) ( $t$ -test,  $P = 0.004$ , 95% CI 1.2–5.8) than those

**Table 2.** Principal cause of blindness in blind cohort ( $n = 59$ ) by gender

	Male	Female	Total	%
Retinal problems				
Retinal dystrophy	7	5	12	
Albinism	4	4	8	
Retinopathy of prematurity	3	2	5	
Norrie's disease	1	0	1	
Subtotal			26	44
Optic nerve problems				
Optic atrophy	2	6	8	
Optic nerve hypoplasia	4	1	5	
Glaucoma	0	1	1	
Subtotal			14	24
Developmental problems				
Congenital ocular malformation	4	0	4	
Coloboma (including CHARGE syn.)	1	3	4	
Subtotal			8	14
Cortical blindness	2	2	4	
Subtotal			4	7
Neoplasms				
Retinoblastoma	1	0	1	
Glioma, optic chiasm	0	1	1	
Subtotal			2	3
Other				
Marfans syndrome	1	0	1	
Nystagmus	2	1	3	
Not specified, amblyopia	0	1	1	
Subtotal			5	8

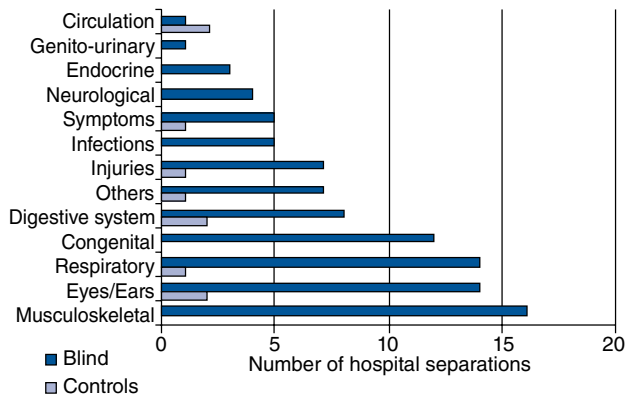
hospitalized (mean 7.4 years, SD 3.8). There was no significant difference in the mean age of the control cohort children with ( $n = 25$ , 7.5 years, SD 4.4) or without ( $n = 34$ , 8.6 years, SD 4.1) hospital separations at the assigned index date ( $P = 0.30$ ).

### Hospital separations

The blind children had 97 hospital separations after the index date of blindness compared with just 10 separations by the normally sighted control children. Thirty-seven per cent of the blind children were admitted as emergency cases. Both blind and controls groups had just one admission each for a single day to ICU. All causes of blindness were associated with an increased number of hospital separations compared with the normally sighted controls. Children with blindness relating to a developmental condition ( $n = 8$ ) had the greatest number of hospital separations (37, mean 4.6, SD 6.9) compared with admissions by the control children ( $n = 59$ ) (10, mean 0.2, SD 0.4,  $P < 0.001$ ). Cortical blindness was also associated with a higher mean rate of hospital separations; four affected children having 11 separations (mean 2.7, SD 2.7) had eight times more hospital separations than the control children ( $P < 0.001$ ).



The most frequently recurring primary diagnosis group was musculoskeletal problems ( $n = 16$ ). Only children who were blind were admitted to hospital for musculoskeletal problems (16 admissions), congenital (12 admissions), ophthalmic (5 admis-



**Figure 1.** Hospital separations, by primary diagnosis groups, for blind children after confirmed blind or for control children after their assigned index date.

sions), infections (5 admissions), neurological (4 admissions), endocrine (3 admissions) or genito-urinary (1 admission) diagnoses (Fig. 1).

There were more than 40 times as many comorbidities recorded by the children who were blind ( $n = 201$ ) compared with the control children ( $n = 5$ ) during these hospital stays.

A negative binomial regression analysis of hospital separations that accounted for the variable length of follow up estimated that the children who were blind had an incident rate ratio 4.2 times greater (95% CI 1.9–9.3) than the control children (Table 3). The model predicted a mean of 1.2 separations (95% CI 0.7–1.6) for each blind child compared with 0.3 separations (95% CI 0.1–0.4) for control children. Socioeconomic status and residential remoteness were not significantly associated with the number of hospital separations.

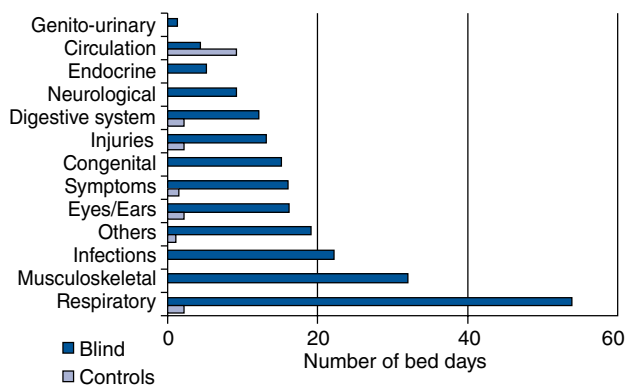
## LOS

The 22 blind and 9 control children with hospital separations after the index date of blindness spent a total of 237 bed days in hospital during the study

**Table 3.** Negative binomial regression and predicted means: number of hospital separations and number of bed days after legal blindness was confirmed

Admissions	IRR	P value	95% CI	Predicted mean separations/period	95% CI
Vision					
Controls	1	–	–	0.3	0.1–0.5
Blind	4.2	<0.001	1.9–9.3	1.2	0.7–1.6
Respiratory infections					
No	1	–	–	–	–
Yes	3.0	<0.001	1.6–5.7	–	–
Cause of blindness					
Controls	1	–	–	0.2	0.1–0.4
Retinal	3.4	0.003	1.5–7.8	0.7	0.2–1.3
Optic nerve	8.3	<0.001	3.2–21.3	1.8	0.6–3.0
Cortical	18.1	<0.001	3.5–91.7	3.9	–1.7–9.4
Developmental	7.6	0.001	2.4–24.0	1.6	0.1–3.1
Neoplasms	n/a	–	–	–	–
Length of stay (days)					
	IRR	P value	95% CI	Predicted mean bed day/period	95% CI
Vision					
Controls	1	–	–	0.5	0.0–1.0
Blind	5.8	0.002	1.9–17.5	2.8	1.3–4.3
Respiratory infections					
No	1	–	–	–	–
Yes	4.1	0.002	1.7–9.9	–	–
Cause of blindness					
Controls	1	–	–	0.5	0.0–0.9
Retinal	2.4	0.06	1.0–5.9	1.1	0.4–1.8
Optic nerve	11.6	<0.001	3.7–36.4	5.4	0.4–10.3
Cortical	37.7	<0.001	6.8–208.1	17.5	–8.4–43.5
Developmental	7.0	0.01	1.6–31.2	3.3	–0.8–7.3
Neoplasms	n/a	–	–	–	–

CI, confidence interval; IRR, incident rate ratio; n/a insufficient data to calculate effect; –, not available.



**Figure 2.** Length of stay, as bed days, by primary diagnosis groups after blindness was confirmed, or for the control children, after their assigned index date.

period (2003–2010). The majority (92%) of days spent in hospital were occupied by the blind children (Fig. 2). The primary diagnoses accounting for the most bed days (25%) were for respiratory problems (54 days), musculoskeletal (32 days) and infections (22 days).

Children with blindness caused by developmental abnormalities spent the greatest number of days in hospital (94 bed days) having five times more days in hospital than controls (19 bed days). The mean number of bed days spent in hospital by all children who were blind (3.7 bed days) was significantly greater than the mean number of bed days of the normally sighted controls (0.3 bed days) ( $P = 0.007$ , 95% CI 1.0–5.8). Of the blind children, those with cortical blindness had the highest mean LOS per admission (34 days, mean 3.1 per admission, SD 3.3), and this was not significantly different from the control children's mean LOS ( $P = 0.33$ ).

A regression analysis of factors affecting the LOS after the index date of blindness adjusting for the variable length of follow up found that the incident rate ratio of bed days was 5.8 times greater (95% CI 1.9–17.5) for the blind children compared with the control children (95% CI 0.0–1.0) (Table 3). The LOS was not associated with either the socioeconomic status or the residential remoteness index.

## DISCUSSION

The hospitalization records of children who were blind illustrate a picture of extensive and complex health issues requiring significant periods of care in tertiary level hospitals. We did not anticipate that respiratory problems would incur the most bed days by this cohort of children, nor that respiratory problems requiring hospitalization were almost entirely among the blind children, affecting a third of all the blind children and accounting for a quarter of all

days spent in hospital. This is made more significant because others have reported high mortality rates among blind children and that these deaths were largely caused by respiratory diseases.<sup>13</sup> In that study, Blohmé and Tornqvist reported that three quarters of deaths were due to pneumonia and that the deaths occurred in adolescence or early adulthood, predominantly in the children who had had additional disabilities combined with their blindness. In our study cohort, we had limited information on other health-related factors. It should also be noted that although there were no recorded deaths in the blind cohort (mean age of 8.2 years), the blind children were survivors up to this age. Children who were blind and died prior to blind registration were not included here.

The distribution of conditions resulting in childhood blindness in our study were broadly similar to those reported by Rudanko and Laatikainen who surveyed a larger cohort of full-term babies who developed either vision impairment or blindness in Finland.<sup>14</sup> Retinal dystrophies were the most frequent cause of childhood blindness in this cohort, followed by albinism and optic neuropathies. Our finding that males were overrepresented in the blind cohort compared with the population gender ratio of male to female children was consistent with other studies of childhood blindness in Europe.<sup>5,13–15</sup>

The strengths of this study were that it included all the legally blind children listed on the blind register in Western Australia in mid-2009, plus an additional nine unregistered blind children who were identified through paediatric ophthalmology clinics. The combined blind cohort represented approximately half of the estimated total population of blind children in Western Australia at the time and would therefore be broadly representative of the whole population of blind children.<sup>6</sup> The study was also strengthened by a previous validation assessment of clinical data contained in the Western Australian blind register.<sup>10</sup>

We restricted the analysis of hospital admissions to those events that occurred only after the children's blind status had been confirmed so that a comparative level of vision impairment was achieved across all the children in the blind cohort. This methodology excluded bias in the data arising from extended periods spent in hospital by a small number of premature babies or those born with severe perinatal problems.

The limitations of this study include the small sample size due to the low prevalence of childhood blindness. Despite this, we were able to demonstrate significant differences in the hospitalization rates compared with normally sighted control children and between the different causes of childhood blindness. Small subgroup population sizes, however,

limited the possibilities of drawing conclusions on separate entities. Although matched cohort studies in a one-to-one ratio have been published recently, this study may have benefited from increasing the number of control children two or three times that of the children who were blind.<sup>16</sup>

Clinical and hospital morbidity records on which this study relied may not be totally comprehensive. Vision loss or blindness was only recorded in the hospital morbidity records of two of these children admitted to hospital as a comorbid condition. The clinical details of the causes and levels of vision loss in children listed on the blind register were also occasionally non-specific, incomplete or out of date.

We found that blindness in childhood was associated with frequent and extended periods in tertiary hospital care and presents a significant public health issue. We found that blindness was rarely recorded as a comorbid condition. The incidence of respiratory illness in the blind children was unexpected and a cause for concern as it may lead to serious morbidity and mortality in these children. Further study of the relationship between respiratory illness and blindness in children is warranted. Cooperative and complementary relations between ophthalmologists, paediatricians and support service providers are required to ensure best practice health service provision for children who are blind.

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# Mortality and hospital morbidity of working-age blind

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## ABSTRACT

**Aim** Determine whether blindness in people aged 18–65 years was associated with increased rates of mortality, hospitalisation and length of stay.

**Methods** A retrospective matched cohort study of legally blind people and normally sighted controls, aged 18–65 years, comparing mortality rates and hospital morbidity records.

**Results** Together, 419 blind and 419 controls accumulated 12 258 hospital separations over the 11-year study period. The blind had an age-specific mortality rate seven times greater (12/1000 person years) than the general population (1.8/1000 person years) ( $p<0.001$ ). Blindness was recorded as a comorbid condition for 76 (22%) blind individuals, on just 255 (2.3%) hospital separation records. Psychiatric, mental or behavioural conditions were the most frequently recorded diagnoses, after dialysis and endocrine conditions. After adjusting for comorbidities, the blind cohort had 1.5 times more hospital separations ( $p=0.007$ , 95% CI 1.1 to 2.0) and 2.2 times more bed days ( $p=0.016$ , 95% CI 1.4 to 4.1) compared with the control cohort.

**Conclusions** Recognition and acknowledgement of in-patients' blind status may assist in understanding the frequent and extended health service utilisation rates. Encouraging and promoting the uptake and access to rehabilitation support services would be measures that may reduce the health service burden of blindness, the incidence of depression and other mental health problems.

## INTRODUCTION

The impact of blindness is widely studied and acknowledged as one of the most severe of disabilities; decreasing personal independence and mobility, often leading to social isolation and depression,<sup>1</sup> adversely impacting quality of life, susceptibility to injury and the financial status of individuals.<sup>2–6</sup> Blindness in Australia and in other developed countries is a condition normally associated with older aged groups.<sup>7</sup> There is, however, very little information on the health and well-being of people of working-age, who are blind.<sup>8–9</sup>

This study identified a large cohort of legally blind people aged less than 65 years from the state register of people with vision impairments. Australia does not currently have a national database of people with vision impairments. In Western Australia (WA), there is a single service provider; the Association for the Blind of Western Australia (ABWA), and registration with ABWA is voluntary. We have previously validated the accuracy of the register as a data resource;<sup>10</sup> the completeness of the register was also assessed using a capture and recapture method.<sup>7</sup> This study cohort was estimated to include more than half of the blind

population of adults aged 18–65 years in WA. We subsequently linked these cohorts, at the individual person level, to the state-wide Hospital Morbidity Data System (HMDS) via the West Australian Data Linkage System.<sup>11–12</sup>

We present an examination of the impact of blindness on mortality and general health using data linkage and hospital morbidity records of hospitals throughout the state.

## METHODS

Using a matched cohort study design, we examined the frequency of admission to and time spent in hospital due to acute disease and increased comorbidity burden, combined with non-acute vision loss, the socioeconomic status and accessibility to services of people aged 18–65 years.

Study data were obtained from the WA state blind register and the WA Data Linkage System following approval from the Curtin University Human Research Ethics Committee and by the Department of Health of Western Australia Human Research Ethics Committee. The study adhered to the tenets of the Declaration of Helsinki.

**Blind cohort:** All adults listed on the state blind register, aged between 18 and 65 years at the index date of registration, were included in the cohort of blind individuals. Legal blindness was confirmed by a specialist ophthalmologist and was defined as having a best-corrected visual acuity of LogMAR  $>1$  or a visual field restriction of  $<10^\circ$  from central fixation, or a combination of both reduced visual acuity and field loss resulting in an equivalent level of disability, in the better eye.

**Control cohort:** A random selection of normally sighted, age-matched ( $\pm 2$  years) and gender-matched adults was derived from the state electoral role of WA (where voting is compulsory for all adults). Matching was provided in a ratio of 1:1 blind to controls. A de-identified extract of all hospital morbidity records from the WA Hospital Morbidity Data collection and any death records from the death register pertaining to individuals in the two cohorts were obtained. Matching, linkage and de-identification of all in-patient hospital morbidity and mortality records were carried out by the Data Linkage Branch of the Department of Health, WA.

This study compared the frequency of hospital separations and cumulative length of stay (LoS) in hospital over an 11-year period, or to the date of death if earlier. A same-day hospital separation was considered as a LoS of 1 day. The total number of hospital separations and cumulative number of days in hospital excluded any inter-hospital or nested transfers.

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**Table 1** Demographics of blind and control cohorts

	Controls	Blind	Total	p Value
Gender				
Male	210	210	420	
Female	209	209	418	
Total	419	419	838	
Age at index date (years)				
18–29	52	55	107	
30–39	67	69	136	
40–49	85	80	165	
50–59	121	132	256	
60–65	90	82	172	
Employment status (%)				
Employed	166 (40)	92 (22)	258	$\chi^2$ 0.002
Unemployed	10 (2)	19 (4)	29	
Pensioner	12 (3)	88 (21)	100	
Other, student, home duties, retired	122 (17)	79 (19)	201	
Missing	109 (26)	141 (34)	250	
Marital status (%)				
Never married	55 (18)	106 (31)	161	
Divorced or separated	18 (6)	32 (9)	50	
Married	223 (72)	183 (54)	406	
Residential geographic region (%)				
Major city	217 (52)	266 (64)	483	
Inner regional	36 (9)	40 (9)	76	
Outer regional	37 (9)	21 (5)	58	
Remote and very remote	18 (4)	14 (3)	32	
Unknown	111 (26)	78 (19)	189	
Mean socioeconomic index	938.5	828.2	880.6	t test <0.001
p Value, probability.				

The Accessibility and Remoteness Index of Australia (ARIA+) at the time of hospital separation was divided into four broad levels of remoteness: major cities, inner regional, outer regional, and remote and very remote regions of Australia.<sup>13</sup> An Index of Relative Socio-economic Disadvantage (IRSD) was assigned to each person's residential address at the time of last hospital separation. The IRSD had four categories dividing the population into quartiles of disadvantage (one most disadvantaged to four least disadvantaged).

Charlson's comorbidity index was used to adjust for the effects of comorbid conditions on the number of separations and LoS.<sup>14</sup> This index consisted of 17 separate diagnosis codes, weighted according to the mortality risk as described elsewhere.<sup>15</sup> The total weighted index was divided into four discrete intervals of increasing morbidity (0, nil comorbidities; 1, 1–2 comorbidities; 2, 3–4 comorbidities; and 3,  $\geq 5$  comorbidities).

Descriptive statistics were used to compare mortality rates, separation rates and LoS of the blind and control cohorts. To account for any similarity (lack of independence) between cases and their matched control, generalised estimating equations assuming a negative binomial distribution were used to estimate incident rate ratios (IRR) after accounting for the variable length of the follow-up periods for each individual. A purposeful backward step-wise selection of variables was performed to generate the most parsimonious regression models. Variables tested for inclusion were gender, age, socioeconomic status, remoteness index and comorbid conditions. Analysis was carried out using IBM PASW V.18 (IBM Corporation, Armonk, New York, USA) and Stata V.12 (StataCorp LP, Texas, USA).

**RESULTS**

The matched cohorts consisted of 419 legally blind adults, 210 males and 209 females (median age 50.3, range 18–65 years) and 419 age-matched and gender-matched controls. When combined,

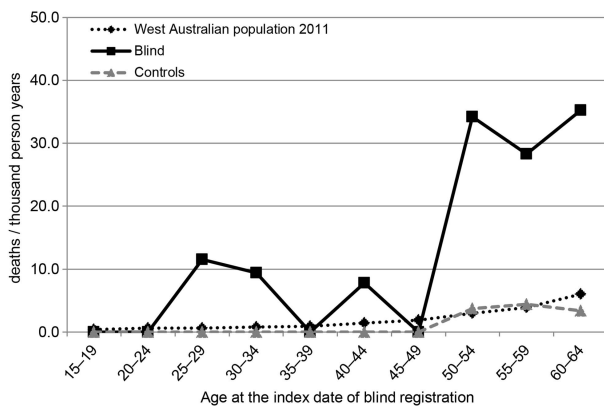
**Table 2** Hospital separations and length of stay (days) of blind and control cohorts during the study period (mid-1999 to mid-2010)

	Controls	Blind	Total	p Value
People with any hospital discharge (%)				
Yes	310 (47)	343 (53)	653	–
No	109 (59)	76 (41)	185	0.006*
Admission type (%)				
Emergency	214 (15)	1244 (85)	1458	–
Elective	1027 (9)	9873 (91)	10 900	<0.001*
Hospital separations (%)				
Before index date legal blindness	645 (14)	4049 (86)	4694	–
After index date legal blindness	596 (8)	7068 (92)	7664	<0.001*
Total	1241	11 117	12 358	
Total bed days (%)				
Before index date legal blindness	1769 (12)	13 376 (88)	15 145	<0.001†
After index date legal blindness	1562 (11)	12 758 (89)	14 320	<0.001†
Total	3331 (11)	26 134 (89)	29 465	<0.001†
Psychiatric care				
People receiving psychiatric care (%)	5 (18)	22 (82)	27	0.001*
Separations for psychiatric care (%)	24 (3)	675 (97)	699	<0.001*
Total days of psychiatric care (%)	117 (8)	1262 (92)	1379	0.23†
Mean length of each stay (SD)	8 (8)	4 (9)	–	0.07†
Mean days per person (SD)	23 (31)	57 (110)	–	0.23†

\* $\chi^2$  test.

†t test.

p Value, probability.



**Figure 1** Age-standardised mortality rates as deaths per thousand person years for blind, controls and the Western Australian population.

the cohorts accumulated 12 258 hospital separations for a total of 29 465 bed days during the 11-year study period (1999–2010). The median length of follow-up was 10.9 years (range 4.5–11 years). None of the controls appeared on the blind register or had any hospital comorbidity coding for blindness and were presumed to be normally sighted. Demographic characteristics are shown in table 1, and hospitalisation events are shown in table 2.

Of the study population, 28 died between the index date and the study end date, with significantly more deaths in the blind cohort ( $n=25$ , 6%) compared with the control cohort ( $n=3$ , 1%) ( $\chi^2$ ,  $p<0.001$ ). The mean length of time from the index date to death was 2.3 years (SD 1.8, range 0.2–6.1 years). The age-standardised mortality rate was ten times greater for the blind cohort (12/1000 person years, 95% CI 6.3 to 16.9) than the control cohort 1.2/1000 person years (95% CI 0 to 2.8). The WA population mortality rate (aged 18–65 years in 2011) was 1.8/1000 person years (95% CI 1.8 to 1.9)<sup>16</sup> (figure 1).

In this cohort of adults of working age, there were significantly fewer blind people ( $n=92$ ) who were employed compared with the control group ( $n=166$ ,  $\chi^2$   $p=0.002$ ). Almost twice as many blind males ( $n=57$ ) were employed compared with blind women ( $n=35$ ), which was disproportionate compared with the control cohort employed (males=95, females=71).

### Cause of blindness

Almost 30% of blindness in this cohort resulted from a congenital retinal dystrophy (retinitis pigmentosa  $n=83$ , Stargardt's  $n=15$ , Usher's  $n=7$ , rod/cone dystrophies  $n=6$  and unspecified dystrophies  $n=15$ ). Diabetic retinopathy, glaucoma and optic nerve pathologies each accounted for more than 10% of cases (table 3). The age at the index date of blindness illustrates the rapid development of blindness due to diabetic retinopathy in those aged over 40 years (figure 2).

### Comorbidity

Blindness was recorded as a comorbid condition in the HMDS records of just 76 (22%) blind individuals admitted to hospital and on just 255 (2.3%) hospital separation records. In total, 41 of the 76 patients coded as being blind in their hospital records were identified prior to the index date of blind registration. Twenty-eight blind (7%) and three controls (<1%) had a Charlson comorbidity index of five or greater. Most (80%) people with diabetic retinopathy had comorbidity scores of 1 or greater (figure 3).

### Hospital separations

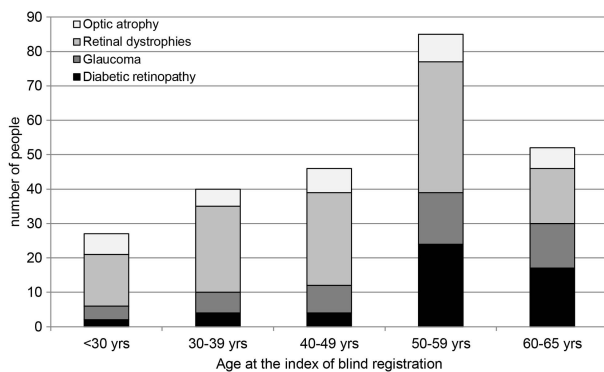
Overall, the blind cohort had more than seven times as many hospital separations compared with the matched control cohort. However, 64% ( $n=7748$ ) of separations were for renal dialysis alone, incurred by just 25 individuals who were blind. Forty-three blind individuals were admitted to intensive care units (ICUs) for 54 separations in contrast to just 15 controls having 20 ICU separations over the study period.

**Table 3** Major contributing causes of blindness for those in the blind cohort, with and without hospital separations and median age at the index date of blindness

Cause of blindness	People with nil hospital separations, n (%)	People with $\geq 1$ hospital separations, n	Total n	Per cent of cohort	Median age at the index, years
Retinal dystrophies	37 (31)	84	121	28.9	47
Diabetic retinopathy	3 (6)	48	51	12.2	56
Glaucoma	1 (2)	45	46	11.0	52
Cataract	3 (9)	31	34	8.1	55
Other macular/retinal	7 (21)	26	33	7.9	57
Optic atrophy	6 (19)	26	32	7.6	57
Optic neuropathies	3 (10)	26	29	6.9	49
Age-related macular degeneration	6 (22)	22	27	6.4	57
Congenital or familial	4 (20)	16	20	4.8	55
Cerebral vascular accident	0	16	16	3.8	51
Cornea	1 (9)	10	11	2.6	51
Neoplasms	0	10	10	2.4	53
Retinal detachments	1 (14)	6	7	1.7	48
Retinal vascular disease (occlusions)	0	6	6	1.4	63
Trauma/surgery	0	2	2	0.5	45
Other or missing			45	10.7	
Subtotal of causes of blindness			463		
Total number of blind individuals			419	100	50

Cumulative total exceeds the total number of individuals ( $n=419$ ) as more than one causal factor may have contributed to blindness.

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**Figure 2** Age at the index date of blind registration and the number of people affected by the four principal causes of blindness, n=250 (60% of study cohort).

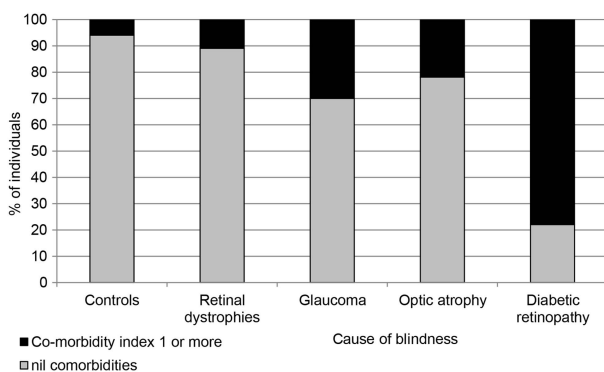
The blind cohort had more hospital separations than controls for all the major diagnostic groups, except for neoplasms (blind n=41, controls n=54) and obstetric problems (blind n=34, controls n=73). Forty-four blind people (10%) were hospitalised with a primary diagnosis of 'care involving rehabilitation procedures' compared with just two controls (0.5%). Four times as many blind people (n=22) were hospitalised for periods of psychiatric care compared with controls (n=5). The blind individuals had 20 times as many separations from psychiatric care facilities (n=296) than controls (n=14) (figure 4).

After adjusting for comorbidities and accounting for the length of follow-up, the blind cohort had 1.5 times more hospital separations ( $p=0.007$ , 95% CI 1.1 to 2.0) than controls. This equated to a mean of 16 separations (95% CI 12.3 to 19.0) for each blind person compared with 10 separations (95% CI 7.2 to 13.4) for controls over the study period. Increasing comorbidity scores were also associated with significantly greater IRR (table 4A).

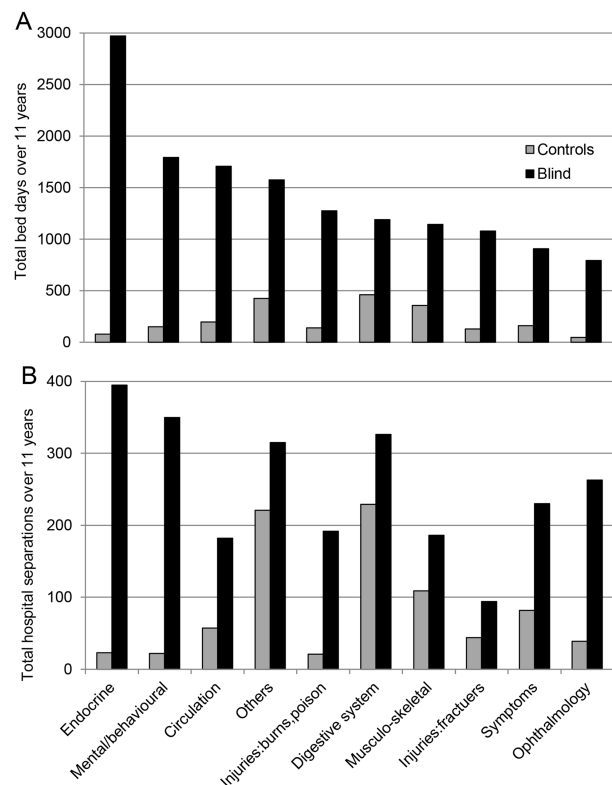
Eight per cent (844) of all hospital separations in this cohort of working-age blind people resulted in a transfer to a nursing home compared with just 0.2% (3) in the control cohort.

### Length of stay

During the study period, the blind cohort accrued 26 134 bed days compared with 3331 by the control cohort. However, 25 blind individuals receiving renal dialysis accounted for more than a quarter of all the bed days occupied (7860 bed days).



**Figure 3** Percentage of people with a comorbidity index score of zero or  $\geq 1$ : controls or people blind due to one of the four main causes of blindness. Comorbidity index scores: Charlson's weighted scores.



**Figure 4** (A) The total number of bed days (excluding dialysis) accumulated over the 11-year study period for the most frequent primary diagnosis groups. (B) The number of hospital separations over the same period for the same diagnostic groups.

Blind people occupied more bed days in every primary diagnostic group compared with controls. The primary diagnoses accounting for the greatest number of days in hospital, other than renal dialysis, were endocrine problems (2973 days), followed by mental or behavioural problems (1794 days), circulatory problems (1709 days), 'other conditions' (including follow-up after neoplasms, adjusting implants and devices, rehabilitation and transition to appropriate accommodation) and injuries resulting from burns or poisoning (1274 days). Although blind individuals were admitted to hospital for ophthalmic conditions over 300 times, the number of bed days accumulated for ophthalmic treatments (n=794 days) was considerably less than other major diagnostic causes (figure 4).

Excluding admissions that were for dialysis only, the unadjusted median LoS for people who were blind (5 days, SD 12.3) was twice as long as the median LoS for controls (2.6 days, SD 4.8) ( $p<0.001$ , 95% CI -3.5 to -2.1). After adjusting for comorbidities and dialysis, this relationship remained significantly greater ( $p=0.016$ ) (table 4B).

More than three times as many blind people (n=30) compared with controls (n=9) were admitted to hospital for the treatment of mental or behavioural conditions. Of these, 22 (73%) blind and 5 (55%) controls also had periods of psychiatric care. The blind cohort accrued 1262 days and controls 296 days as in-patients of psychiatric care units.

### DISCUSSION

In this relatively young and blind cohort, we found a strong association between blindness, the frequency of admission and LoS in acute care hospitals in WA. The blind also had a



**Table 4** Negative binomial regression analysis and predictive margin: (A) number of separations and (B) length of stay (days)

	IRR	p Value	95% CI	Predictive margin	95% CI
<b>A. Discharges</b>					
Vision					
Controls	1			10.3	7.2 to 13.4
Blind	1.5	0.007	1.1 to 2.0	15.6	12.3 to 19.0
Dialysis					
No	1				
Yes	24.4	0.000	16.6 to 35.7		
Comorbidity score					
0	1				
1	2.2	0.002	1.3 to 3.7		
2	2.2	0.000	1.5 to 3.3		
3	3.3	0.000	2.3 to 4.7		
Remoteness score					
Major city	1				
Inner regional	0.8	0.17	0.6 to 1.1		
Outer regional	0.8	0.31	0.6 to 1.2		
Remote and very remote	0.8	0.25	0.6 to 1.1		
Socioeconomic score					
Most disadvantaged	1				
More disadvantaged	1.2	0.12	0.9 to 1.5		
Less disadvantaged	1.3	0.18	0.9 to 2.1		
Least disadvantaged	1.1	0.49	0.8 to 1.4		
<b>B. Length of stay (days)</b>					
Vision					
Controls	1			24.6	8.2 to 40.9
Blind	2.2	0.016	1.4 to 4.1	53.5	36.8 to 70.2
Dialysis					
No	1				
Yes	9.2	0.000	5.3 to 16.2		
Comorbidity score					
0	1				
1	4.8	0.019	1.3 to 18.0		
2	3.6	0.000	2.0 to 6.7		
3	6.5	0.000	3.6 to 11.9		
Remoteness score					
Major city	1				
Inner regional	0.8	0.22	0.5 to 1.2		
Outer regional	0.7	0.11	0.5 to 1.1		
Remote and very remote	0.7	0.05	0.5 to 1.0		
Socioeconomic score					
Most disadvantaged	1				
More disadvantaged	1.4	0.08	1.0 to 2.1		
Less disadvantaged	1.3	0.26	0.8 to 2.0		
Least disadvantaged	1.1	0.79	0.6 to 1.8		

IRR, incident rate ratio; p value, probability.

significantly higher mortality rate compared with the age-standardised population mortality rate. The study cohort was estimated to include at least half of all the legally blind people aged 18–65 years at the time in WA and, as such, was broadly representative of the working-age blind population as a whole.<sup>7 17</sup>

Rahi *et al* did not find an association between severe vision impairment and the self-reported hospitalisation events in a UK birth cohort (aged 50 years), which included 0.3% (n=29) individuals who were severely vision impaired or blind. However, the authors acknowledged that the study was underpowered to detect any such associations.<sup>9</sup> The current study has shown that young people who became blind during their working life were

more frequently admitted to ICUs as emergency admissions and experienced more frequent and prolonged periods of in-patient psychiatric care.

The predicted mean number of days in hospital per year for the blind was double that of the controls. This finding was consistent with that of Morse *et al*,<sup>18</sup> who analysed US health insurance data of a large cohort described as ‘primarily legally blind’ but where the visual acuity was not tested and the hospital case mix was somewhat different.

The strengths of this study are the ability to combine large health-related data sets at the individual person level across the whole state population, thereby avoiding bias limitations associated with analysis of single-centre studies. This study is also

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strengthened by having the level of vision loss defined and confirmed in all cases by a qualified ophthalmologist. Similarly, the blind register was validated in an earlier study by two independent ophthalmologists.<sup>10</sup> However, by selecting the blind cohort from the register of a service provider, it is likely that the individuals in the blind cohort would have accessed a range of rehabilitation services in contrast to blind people who have never been registered or received support services. This may result in an underestimation of the full extent of the healthcare burden of blindness in WA.

Vision impairment and blindness have previously been linked to an increased risk of death.<sup>19 20</sup> Eighty years ago, a life insurance company in the USA reported that blind clients had a mortality rate more than double that of non-blind clients.<sup>21</sup> In the current study, the age-specific mortality rate of this younger blind cohort was seven times greater than that of the normally sighted controls and also of the state population aged 18–65 years. While we did not have details of the specific causes of death, we did note that most of the blind people who died in this cohort had been hospitalised for either diabetes with multiple comorbid conditions or were admitted for treatment of problems of the circulatory system.

It was disappointing to note that 75% of legally blind patients admitted to hospital did not have their blind status recorded as a comorbid condition in their hospital records. These data, together with an earlier report,<sup>22</sup> suggest that hospital clinicians and/or coding staff did not recognise vision loss at the level of legal blindness to be a relevant or significant comorbidity contributing to the health and well-being of patients.

While only a small proportion of individuals in the blind cohort were admitted to hospital for the treatment of mental or behavioural problems, the majority of these cases went on to receive extended periods of in-patient psychiatric care. These data support the more widely reported incidence of mental illness and depression estimated to affect up to a third of severely vision impaired and blind people.<sup>23</sup> Depression per se would not be generally treated in an acute care hospital setting, and therefore data available in this study would not accurately reflect the extent of depression in either the blind cohort or control cohort. Rather, the in-patient treatment of people with mental or psychiatric problems could be viewed as the extreme end of this spectrum of illnesses, which include depression, behavioural, mental and psychiatric conditions. Rehabilitative care was prescribed to just 10% of blind people in this cohort.

The current study did not take into account the personal impact of blindness on quality of life<sup>24</sup> nor the economic burden of reduced productivity where less than a quarter were employed and so the full extent of the burden of blindness is only partially reflected in these hospitalisation rates. However, we conclude that legal blindness contributes to an increased frequency of admission to and extended LoS in hospital. The specific reasons for these extended periods in hospital may be a consequence of poorer mobility skills, confusion or disorientation in the hospital setting, leading to issues of health and safety. Hospital stays may be extended to accommodate surgical or medical follow-up for blind patients with transport difficulties or there may be concerns regarding the discharge of blind patients with revised or new medication regimens.

Recognition and acknowledgement of in-patients' blind status may assist in understanding the frequent and extended health service utilisation rates. Encouraging and promoting the uptake and access to rehabilitation support services would be measures that may reduce the health service burden of blindness, the incidence of depression and other mental health problems. A better

understanding of the specific needs of patients who are blind could reduce additional days in acute care hospitals and therefore also healthcare costs.

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**Contributors** JMC: overall study coordination. Responsible for data analysis and interpretation, database security and validation checking. Drafted, formatted and critically revised manuscript for peer review. AC: ophthalmic registrar who assisted with clinical data acquisition, analysis, statistical advice and provided final approval for the manuscript to be submitted for peer review. KS: biostatistician, provided essential analysis, significant critical comment and final approval for the manuscript to be submitted for peer review. ASM: IT support with responsibility for data acquisition, extraction, data management and provided final approval for the manuscript to be submitted for peer review. NM: clinical consultant ophthalmologist, provided a substantial contribution to conception of study design and clinical support for the project. Critically reviewed the manuscript providing important intellectual content. WHM: clinical consultant ophthalmologist, provided a substantial contribution to conception of study design, clinical support for the project and final approval for the manuscript to be submitted for peer review. JBS: chief investigator with overall responsibility for the research project. Had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the analysis. Critically reviewed the manuscript and provided final approval for the manuscript to be submitted for peer review.

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## Original Article

# Diabetic retinopathy and the major causes of vision loss in Aboriginals from remote Western Australia

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## ABSTRACT

**Purpose:** To report on diabetic retinopathy (DR) and the major causes of vision loss and blindness in Aboriginals in the Eastern Goldfields region of Western Australia between 1995 and 2007.

**Methods:** Aboriginals (>16 years old) diagnosed with diabetes or eye problems from 11 communities in the Eastern Goldfields region of Western Australia were examined annually from 1995 to 2007. Data collected from prospective clinical examination included; visual acuity (VA), causes of vision loss, and whether DR was present. Severity of DR was graded according to the Early Treatment of Diabetic Retinopathy Study modified Airlie House grading system.

**Results:** A total of 920 Aboriginals underwent 1331 examinations over the study period. There were 246 eyes with vision loss (best-corrected VA < 6/12) in 159 Aboriginals, of whom five were bilaterally blind. The four major known causes of vision loss were cataract ( $n = 53$ , 30.1%), DR ( $n = 44$ , 25.0%), uncorrected refractive error ( $n = 31$ , 17.6%) and trauma ( $n = 19$ , 10.8%). Aboriginals who had diabetes were far more likely to have vision loss (odds ratio = 8.5, 95% confidence interval 5.7–12.6,  $P < 0.0001$ ). Of the 329 Aboriginals with diabetes, 82 (24.9%)

had DR, and 32 (9.7%) had vision-threatening retinopathy. Of those with diabetes, 94 (42.5%) returned for follow-up examination on an average of 3.2 visits with a median time between visits of 2 years.

**Conclusion:** The four major causes of vision loss in Aboriginals from the Eastern Goldfields are largely preventable and/or readily treated. DR and other diabetes-related eye conditions are a major cause of vision loss in Aboriginals, representing a significant health challenge for health services and clinicians into the future.

**Key words:** Aboriginal Australian, blindness, diabetic retinopathy, epidemiology, low vision.

## INTRODUCTION

The National Trachoma and Eye Health Program (NTEHP) brought awareness to Australian Aboriginal eye health in the mid 1970s.<sup>1</sup> They reported the prevalence of eye disease among Aboriginal Australians compared with the general population was up to 10 times more common and blindness twice as common, and that the majority of vision loss was due to preventable or treatable conditions.<sup>2</sup> Recent studies have shown little has changed and that vision loss in Aboriginal people is still due to preventable or treatable conditions including cataract,

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diabetic retinopathy (DR), uncorrected refractive error, trachoma and trauma.<sup>3-8</sup>

The inclusion of DR as an important cause of vision loss in Aboriginal communities is new since the NTEHP when no cases were reported.<sup>1</sup> Diabetes has become particularly concerning for eye health in Australian Aboriginals due to its dramatic rise in prevalence in recent decades. Up to 20% of Australian Aboriginals have diabetes compared with 7% in the general community,<sup>9,10</sup> with 25% having some signs of DR.<sup>11</sup> The implications for Aboriginal eye health are significant not only due to the expected increase in DR but also due to the increase in other diabetes-related eye conditions, for example, cataract, retinal vascular disease and neovascular glaucoma.

Most data on Australian Aboriginal eye health have been derived from short-lived cross-sectional surveys of remote communities.<sup>7,8,12-15</sup> One major difficulty of these surveys is variable ascertainment due to the transient nature of remote Aboriginal people. The Goldfields Eye Health Survey (GEHS) began in 1992 as a yearly public health screening initiative to evaluate and manage eye health problems, namely trachoma, in Aboriginal communities in the Goldfields region of Western Australia (WA) (Fig. 1).<sup>16</sup> We realized that repeated examinations of these remote communities, whose population is highly mobile, would allow more complete ascertainment of various diseases over time. In 1995, DR screening was commenced and DR grades recorded for all Aboriginals

with diabetes examined. After 16 years, the GEHS is the longest running Aboriginal eye health survey in Australia. The aim of this paper is to report on data collected in the GEHS on DR and the major causes of vision loss over 12 years in Aboriginals from the Eastern Goldfields region of WA.

## METHODS

### The goldfields eye health survey

All residents of the Eastern Goldfields communities visited in each year were eligible to attend the visiting eye clinics. The communities visited are isolated and scattered across the region and included Kalgoorlie, Coolgardie, Norseman, Coonana, Cosmo Newberry, Laverton, Leonora, Menzies, Mt Margaret, Tjuntjunjarra and Wiluna (Fig. 1). The average resident Aboriginal population in the region over the study period was 3980 (range 3645–4372) of which 1384 resided in remote communities (Epidemiology Branch, Health Information Collection, Department of Health of Western Australia).

The visiting ophthalmology team comprised an ophthalmologist, a training ophthalmology registrar and a nurse. Local community nurses and Aboriginal Health Workers (AHW) also assisted during each visit. Those who had an eye complaint, vision problem or who were diabetic were particularly sought out by the visiting team and were transported to the local community health centre to be examined.

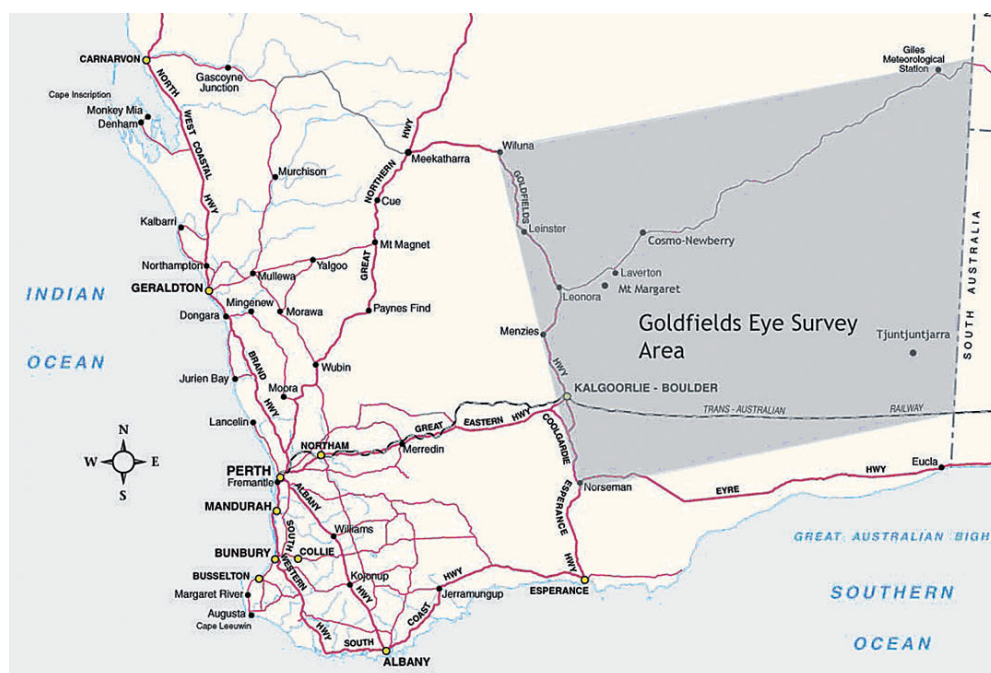


Figure 1. The Eastern Goldfields Eye Health Survey Area, Western Australia.



Those unable to attend, such as the frail or elderly, were seen in their homes.

Where possible all subjects had their visual acuity (VA) measured (with current spectacles if they were worn); and dilated indirect and direct ophthalmoscopy was performed to examine the posterior segment and ocular media. Those with a VA worse than 6/12 were refracted before dilation.

The logistics of ensuring maximal service delivery are significant given the size of the area and transience of the local Aboriginal population. The visiting team worked very closely with the regional Public Health Department and community AHWs and nurses to select the most suitable time to visit. Precise timing was chosen closer to each visit to avoid local ceremonies or cultural events that were likely to diminish the Aboriginal population available for screening.

## Data collection

Clinical information was recorded prospectively between 1995 and 2007 inclusive, except 2000 when no survey was conducted for logistical reasons. In 2003, clinical information was entered into an electronic database and all subsequent survey visits were recorded on this database. This allowed people diagnosed with diabetes in the communities to be identified in subsequent visits and a review initiated. Approval was obtained from local Aboriginal Community Councils in the region for the use, analysis and reporting of the data collected.

## Definitions

The presenting VA was that defined as that measured at the time of each visit on a standard Snellen chart. If spectacles were worn then the VA with the current correction was recorded. Vision impairment (VI) was defined as a presenting VA worse than 6/12. Blindness was defined as a presenting VA worse than 6/60. VI was attributed to refractive error if the best-corrected VA was better than or equal to 6/12. Similarly, blindness was attributed to refractive error if the best-corrected VA was better than or equal to 6/60.

The cause of vision loss in eyes was attributed to the major disease present. Where two or more diseases were present the cause was attributed to that which was felt to be the greatest contributor to vision loss.

The simplified World Health Organization trachoma grading scheme was used to grade trachoma.<sup>17</sup> DR was graded according to the Early Treatment of Diabetic Retinopathy Study modified Airlie House grading system.<sup>15</sup> Peripheral DR was graded as

'mild', 'moderate' or 'severe' non-proliferative retinopathy, and proliferative DR (PDR). Diabetic maculopathy was graded as Grade 1 (hard exudates within 1 disc diameter of the centre of the macula), Grade 2 (hard exudates or retinal thickening within 500 microns of the centre of the macula) or Grade 3 (hard exudates or retinal thickening beneath the centre of the macula). For clinical simplicity, Grade 1 maculopathy was categorized as diabetic macular oedema not significant, and Grades 2 and 3 considered together as clinically significant macular oedema (CSME). Patients were considered to have vision-threatening retinopathy (VTR) if severe non-proliferative retinopathy, PDR or CSME was present.

Communities visited were grouped into remote and non-remote on the basis of their distance from Kalgoorlie (the major centre within the Goldfields region). We considered communities outside a radius of 250 km from Kalgoorlie as remote, whereas all others were considered non-remote.

## Data analysis

Data were analysed using Stata (Release 10; Stata Corporation, College Station, TX, USA). Population characteristics and the major causes of VI were summarized using simple descriptive statistics. Categorical variables were compared using the chi-squared statistic, and Fisher's exact test where categories were less than five. Mean ages at initial visit were compared using the Student *t*-test. Trends over time in DR severity and the median time to follow-up were assessed using the Spearman rank correlation coefficient.

## RESULTS

Study population characteristics are summarized in Table 1. There were 1331 examinations performed on 920 Aboriginals between 1995 and 2007 including 592 examinations on 329 people with diabetes. The mean age of all participants at their first visit was 42 years (range 16–89 years), with males being slightly older than females (Mean difference 2.4 years, 95% confidence interval [CI] 0.02–4.9,  $P < 0.05$ ) and diabetics significantly older than non-diabetics (Mean difference 10.7 years, 95% CI 9.72–14.10,  $P < 0.001$ ).

There were 159 Aboriginals who had one or more VI or blind eyes (246 eyes), of whom five had binocular blindness (Table 2). In 70 eyes (28.4%) the causes of VI or blindness was unknown or not recorded and were excluded from analysis. Importantly, we found no significant difference in the age or sex distribution of this group of patients compared with those whose diagnosis was known.

**Table 1.** Characteristics of Aboriginals (>16 years) seen in the Eastern Goldfields Eye Health Survey 1995–2007

	All participants ( <i>n</i> = 920)	Diabetics ( <i>n</i> = 329)	<i>P</i> -value†
Examinations ( <i>n</i> )	1331	592	
Age (years)‡			
Male (mean ± SD)	43.1 ± 15.0	48.5 ± 12.2	<0.001
Female (mean ± SD)	40.7 ± 14.7	47.7 ± 13.4	<0.001
Female <i>n</i> , (%)	500 (54.4)	195 (59.3)	0.05
Remote community <i>n</i> , (%)	520 (56.5)	221 (67.2)	<0.001
Vision loss <i>n</i> , (%)§	159 (17.3)	121 (36.8)	<0.001
Monocular vision impairment	88	70	
Monocular blindness	24	22	
Binocular vision impairment	79	57	
Binocular blindness	5	5	

†*P*-values are derived from Student's *t*-test for continuous variables and chi-squared test for categorical variables comparing the diabetic to non-diabetic population. ‡Age was only available for 595 participants. §Persons may contribute to more than one category over the study period.

**Table 2.** Known causes of blind and VI eyes in Aboriginals examined in the Eastern Goldfields Eye Health Survey 1995–2007†

Cause	VI eyes <i>n</i> (%)	Blind eyes <i>n</i> (%)	Total eyes‡ <i>n</i> (%)
Cataract	42 (28.6)	16 (38.1)	53 (30.1)
Diabetic retinopathy	42 (28.6)	7 (16.7)	44 (25.0)
Refractive error	31 (21.1)	0 (0.0)	31 (17.6)
Trauma	8 (5.4)	13 (31.0)	19 (10.8)
Other	10 (6.8)	3 (7.1)	12 (6.8)
Trachoma	3 (2.0)	1 (2.4)	4 (2.3)
Pterygium	4 (2.7)	0 (0.0)	4 (2.3)
Amblyopia	2 (1.4)	1 (2.4)	3 (1.7)
Retinal detachment	2 (1.4)	0 (0.0)	2 (1.1)
Retinitis pigmentosa	2 (1.4)	0 (0.0)	2 (1.1)
Secondary glaucoma	0 (0.0)	1 (2.4)	1 (0.6)
Surgical complication	1 (0.7)	0 (0.0)	1 (0.6)
Total	147 (100)	42 (100)	176 (100)

†The cause of vision loss was not recorded for 70 eyes (three VI eyes, and 68 blind eyes). ‡Eyes may contribute to more than one category over the study period, for example, VI eyes that have progressed to blindness. VI < 6/12, ≥6/60; blind < 6/60. VI, vision impaired.

Aboriginals who had diabetes accounted for 76.1% of patients with vision loss and were significantly more likely to have vision loss compared with those who did not have diabetes (odds ratio = 8.5, 95% CI 5.7–12.6, *P* < 0.001).

The major causes of vision loss are summarized in Table 2. Cataract (28.6%, 95% CI 20.7–35.3), DR (28.6%, 95% CI 20.7–35.3), uncorrected refractive error (21.1%, 95% CI 14.4–27.6) and trauma (5.4%, 95% CI 1.8–9.0) made up the top four causes. There were only three vision impaired eyes due to trachoma. There was no significant difference in the causes of vision loss for men and women.

Trauma accounted for 13 blind eyes (31.0%, 95% CI 16.1–43.9) and was the second most common cause of blindness after cataract (18 eyes, 38.1%, 95% CI 23.3–52.7). DR accounted for seven blind eyes (16.7%, 95% CI 4.9–27.1). There was one blind eye due to trachoma seen in 1997 and none found since that time. In those five people who had binocular blindness; two were due to bilateral cataracts, one due to cataract and DR, and one due to trauma in one eye and cataract in the other. The cause of binocular blindness in the last person was not recorded.

The severity of DR in diabetic Aboriginals seen in each year is summarized in Table 3. Over one-third (35.8%, 95% CI 32.7–38.9) of all patients examined had diabetes, with 82 (24.9%, 95% CI 20.3–29.6) showing signs of DR and 32 (9.7%, 95% CI 6.5–2.9) signs of VTR at least once since 1995. The trend in the proportion who had DR, VTR and CSME showed no significant change over time (Spearman Rank *P* > 0.1) (Fig. 2). Two cases of PDR were seen in 1995, and one case in 1997 and 2006. At their first visit, 18% (95% CI 14.1–22.4) of diabetics had DR, whereas 7% (95% CI 4.2–9.8) had VTR. Two patients had PDR at their first visit.

Ninety-four (42.5%, 95% CI 36.0–49.0) Aboriginal diabetics from remote communities returned for follow-up examination at least once over the study period, on an average of 3.2 occasions. Follow-up time varied across the years (Fig. 3) with the overall median time between examinations being 2.0 years (0.7–10.3 years). Less than half (47.9%) of follow-up examinations occurred within 2 years of the previous exam.

## DISCUSSION

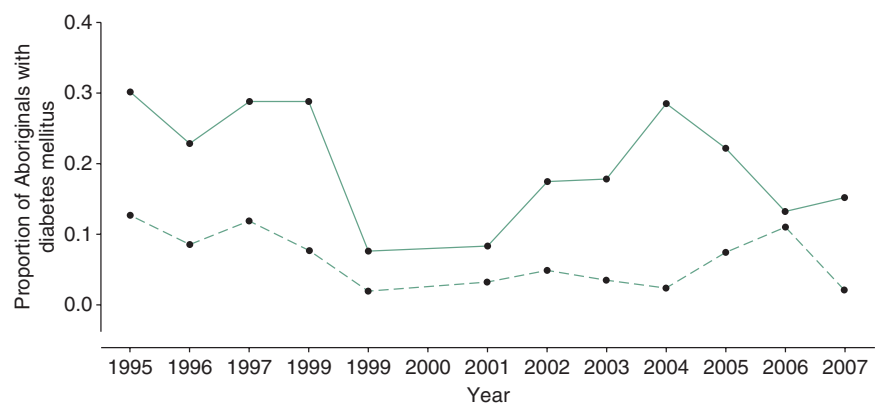
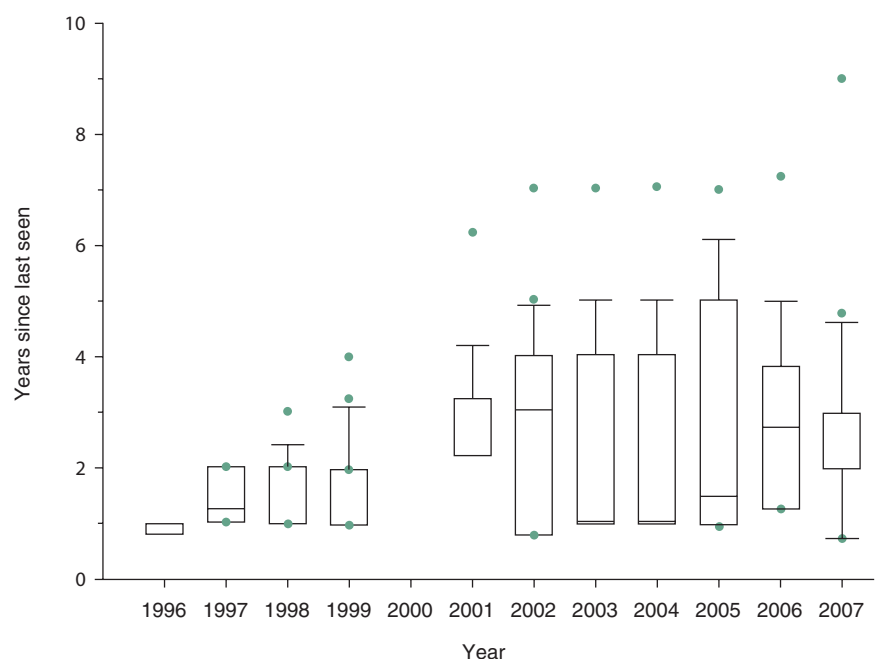
There is a relative paucity of recent data regarding the causes of vision loss in Aboriginal Australians.



**Table 3.** Severity of DR in Aboriginals with diabetes seen in the Eastern Goldfields Eye Health Survey 1995–2007 (n; %)

Period	n	DR	Severity of diabetic retinopathy						
			Macula Oedema		NPDR				VTR
			CSME	DMENS	Mild	Mod	Severe	PDR	
1995–1997	152	44 (28.9)	14 (9.2)	7 (4.6)	21 (13.8)	13 (8.6)	4 (2.6)	3 (2.0)	21 (13.8)
1998–2001	156	24 (15.4)	6 (3.8)	6 (3.8)	11 (7.1)	6 (3.8)	2 (1.3)	0 (0.0)	8 (5.1)
2002–2004	131	29 (22.1)	2 (1.5)	7 (5.3)	20 (15.3)	3 (2.3)	4 (3.1)	0 (0.0)	6 (4.6)
2005–2007	118	19 (16.1)	7 (5.9)	2 (1.7)	7 (5.9)	6 (5.1)	4 (3.4)	1 (0.8)	12 (10.2)
Whole period	329	82 (24.9)	27 (8.2)	20 (6.1)	49 (14.2)	24 (7.3)	13 (4.0)	3 (0.9)	32 (9.7)
At presentation	329	60 (18.2)	19 (5.8)	8 (2.4)	31 (9.4)	15 (4.6)	6 (1.8)	2 (0.6)	23 (7.0)

CSME, clinically significant macular oedema; DMENS, diabetic macular oedema not significant; DR, diabetic retinopathy; NPDR, non-proliferative diabetic retinopathy; PDR, proliferative diabetic retinopathy; VTR, vision-threatening retinopathy (CSME or severe NPDR or PDR).

**Figure 2.** Trend in the proportion of adult Aboriginals with diabetes with diabetic retinopathy seen in the Eastern Goldfield Eye Health Survey 1995–2007. (—), any diabetic retinopathy; (---), vision-threatening retinopathy. (No survey was conducted in 2000.)**Figure 3.** A Box and whisker plot showing the trend in follow-up time in Aboriginals with diabetes from remote communities in the Eastern Goldfields Eye Health Survey 1995–2007. Whiskers mark the upper and lower 5% values; (•) outliers.

**Table 4.** Proportion of diabetics seen with DR and VTR in other Aboriginal communities

Author	Location	Year	DR	VTR
Durkin <i>et al.</i> <sup>11</sup>	Remote, South Australia	1999–2004	21%	12%
Murray <i>et al.</i> <sup>12</sup>	Kimberly region, Western Australia	1999–2004	21%	3.5%
Diamond <i>et al.</i> <sup>13</sup>	Pilbara region, Western Australia	1997	23%	–
Jaross <i>et al.</i> <sup>9,10</sup>	Katherine region, Northern Territory	1996	21%	8.5%
		1993	18%	6.7%
Our study	Goldfields region, Western Australia	1995–2007	25%	9.7%

DR, diabetic retinopathy; VTR, vision-threatening retinopathy.

Ours is the first study to report on the major causes of vision loss and blindness in an Australian Aboriginal population since 1994 and is the first to have collated these data over a period greater than 10 years.

The major causes of VI and blindness in Aboriginals in the Goldfields region differ from previous reports between 15–40 years ago.<sup>2,4,12</sup> In particular, we found a greater association of vision loss with diabetes and a lesser association with trachoma. Some similarities remain especially concerning cataract, which is a significant cause of vision loss, accounting for nearly one-third of VI eyes and contributing substantially to blindness (38%). Although this is an improvement from previous reports, where 40–50% of all blindness was due to cataract,<sup>2,4</sup> it is still over twice that reported in the wider Australian population.<sup>18</sup> These findings reinforce the importance of continuing cataract surgery delivery to these communities where significant barriers to attending surgery are known to exist.<sup>19,20</sup>

It was encouraging that we found few cases of vision loss due to trachoma given its prevalence in previous studies and that it is still endemic in many remote Australian communities.<sup>2–4,12,16,21–23</sup> We have not seen any new blind eyes due to trachoma since 1997, and saw few vision impaired eyes. This represents a significant improvement since the 1970s NTEHP where nearly 10% of Aboriginals had trachomatous monocular or binocular blindness.<sup>2</sup> This is perhaps a reflection of an improvement in living conditions, better community education regarding hygiene and improved access to antibiotics in the region.<sup>16</sup>

Trauma accounted for a significant proportion of blind eyes examined (>1/3) and changed little over the study period. Our findings indicate an improvement from those of Mann who found trauma was the second most common cause of blindness in eyes seen in the Eastern Goldfields region in 1954.<sup>12</sup> However, it is higher than reports from other regions, where approximately one-quarter of blind eyes were due to trauma,<sup>2,4</sup> and may be reflective of increased interpersonal violence reported in Aboriginal communities.<sup>24,25</sup>

Our study confirms the importance of diabetes as a major health issue among Australian Aboriginals. We found over 75% of Aboriginals from the Eastern Goldfields with vision loss also had diabetes, and that having diabetes was associated with an 8.5-fold increase in risk of vision loss from any cause. In terms of DR, a quarter of Aboriginals with diabetes had signs of DR, which contributed to VI in 20% of eyes. This is higher than previously reported in other Aboriginal communities (Table 4) and is significantly higher than in the general Australian population.<sup>7,8,13–15,18</sup> Our observation of 10% with signs of VTR at least once over the study period is similar to that seen in other communities. It is concerning that almost 20% diabetics had signs of DR and a third had VTR at their first visit to the eye clinic. These findings strongly reinforce the need for early and regular ophthalmic review of all diabetics in remote Aboriginal communities.

Less than half of all diabetic patients returned for follow-up and, among those who did, only half were seen within the recommended 2 years.<sup>26</sup> This was despite efforts to recall all diabetic patients using our clinical database. It is possible that these people chose not to attend or were elsewhere at the time the clinic visited. The mobile nature of Aboriginal populations is well described,<sup>27</sup> whether those who weren't in the community at the time of each survey engaged health services elsewhere is not known. Although we found the use of a clinical database to initiate patient recall was a useful tool, as it allowed better monitoring of known diabetic patients, the implementation of such a system on a larger scale could further assist clinicians and health workers in monitoring patients across different health services.<sup>28</sup>

Interestingly, there were no cases of primary open angle closure glaucoma or age-related macular degeneration (ARMD). This compares favourably with the wider Australian community where glaucoma and ARMD contribute significantly to blindness.<sup>29,30</sup> It could be explained by the relatively young study population and the reduced life expectancy of Aboriginal Australians,<sup>31</sup> although it suggests that there may be reduced susceptibility to glaucoma and ARMD among Aboriginals.

Some study limitations exist. We examined 920 (~23%) of the approximately 3980 Aboriginals resident in the WA communities visited. Our ascertainment of cases was unlikely to be complete at every visit since our assessment relied upon voluntary attendances. The mobility of the Aboriginal communities may have also diminished our ability to capture the total population at risk.<sup>27</sup> The data presented may also be subject to selection bias since Aboriginal people who had diabetes or had vision problems were specifically targeted. Therefore, our data may over estimate the contribution of diabetes-related eye disease (e.g. cataract and DR). For these reasons, questions regarding prevalence and trends over time for the major causes of vision loss could not be properly answered from our data. However, the repeated annual surveys over 12 years and the use of local community health workers to find and bring patients have likely maximized case ascertainment within each community.

Our findings reinforce those of previous cross-sectional Aboriginal eye health surveys indicating the main causes of vision loss in Aboriginal eyes are still treatable or preventable. There is a clearly a need to assess ophthalmic services provide to these communities given readily treated conditions, such as cataract and refractive error, remain important causes of vision loss. We are particularly concerned by the threat of diabetes to Aboriginal eye health because of the strong association with vision loss and that no demonstrable improvement in retinopathy was seen, even with large local efforts to encourage review examinations. However, it is encouraging to see significantly reduced rates of trachoma associated vision loss compared with reports from 15 or more years ago.<sup>1,2,4,12</sup>

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## Original Article

## Further survey of Australian ophthalmologists' diabetic retinopathy management: did practice adhere to National Health and Medical Research Council guidelines?

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### ABSTRACT

**Background:** To compare the self-reported management of diabetic retinopathy by Australian ophthalmologists with the 1997 National Health and Medical Research Council (NHMRC) guidelines.

**Methods:** Self-reported cross-sectional survey of patterns of practice. Questionnaires were sent to all Australian ophthalmologists, comprising questions regarding professional details, diabetic retinopathy screening attitudes/practices and specific hypothetical management scenarios. Data were analysed using Chi-squared and adjusted logistic regression.

**Result:** 480 of the 751 (64%) eligible Australian ophthalmologists participated. The majority (80%,  $n = 376$ ) reported they consistently reviewed patient's glycaemic control, but only 55% and 41% regularly reviewed blood pressure and serum cholesterol control, respectively. Ophthalmologists generally adhered to NHMRC-recommended screening intervals, although only 38% agreed with the guidelines relating to screening of pre-pubertal diabetic patients. Fluorescein angiogram was used more than recommended, especially for mild non-proliferative diabetic retinopathy where 45% of respondents used this investigation. Practice duration >15 years was associated with more regular fluorescein angiogram

use (OR = 3.74; 95% CI: 2.53–5.53,  $P < 0.001$ ). In the clinical scenarios where clinically significant macular oedema was concurrently present with cataract or proliferative diabetic retinopathy, >26% referred to retinal subspecialists for management; 85% of the remaining ophthalmologists performed macular laser first. Respondents with practice duration >15 years were 7.8 times ( $P = 0.001$ ) more likely to perform cataract surgery first.

**Conclusion:** Diabetic retinopathy management guidelines were generally well followed by Australian ophthalmologists. However, areas of practice variation existed including frequent use of fluorescein angiogram. Significant proportion of practitioners referred diabetic patients to retinal subspecialists, who were more likely to adhere to guideline recommendations. Ophthalmologists with greater experience (>15 years) were more likely to employ practices differing from NHMRC recommendations.

**Key words:** clinical guideline, diabetic retinopathy, management survey.

### INTRODUCTION

Blindness from diabetic retinopathy (DR) is largely preventable.<sup>1</sup> Despite readily available screening services and treatment facilities in Australia, DR

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remains the leading cause of blindness among working-aged Australians<sup>2</sup> and is a significant economic burden to the Australian health system.<sup>3</sup> Hoping to improve the management of DR, the National Health and Medical Research Council (NHMRC) released the original *Clinical Practice Guidelines: Management of Diabetic Retinopathy* in 1997.<sup>4</sup>

The impact of these guidelines and their implementation were evaluated through national surveys conducted between 1997 and 2000 by the Centre of Eye Research Australia (CERA) to determine the practice patterns of ophthalmologists before and after the guidelines' publication.<sup>5-7</sup> Those surveys found that although the NHMRC guidelines were well received among ophthalmologists, there were few significant changes to management practices towards its recommendations.<sup>7</sup>

A revised version of the NHMRC DR management guidelines was released in late 2008.<sup>8</sup> As nothing is known about ophthalmologist's use of NHMRC guidelines since 2001, we re-examined the contemporary DR management patterns in the present study. Our aim was to identify any changes in management trends over the last decade and provide information to guide the implementation of the revised guidelines, as well as establishing baseline data for future evaluation.

## METHODS

The present study was a cross-sectional survey of currently practising Australian ophthalmologists. A self-administered two-page questionnaire was mailed to all Australian Fellows of the Royal Australian and New Zealand College of Ophthalmologists (RANZCO) ( $n = 751$ ) in November 2007. Further mail-out of surveys to non-respondents was conducted twice in January and February 2008 to help maximize responses. The University of Western Australia Human Research Ethics Committee approved this study.

Questions in this survey were adapted from the previous survey with the assistance of CERA, allowing a direct comparison of results. The questions were related to general professional and practice details; DR screening attitudes and practices (frequency of DR screening and reviewing risk factors, use of reminder notice, confidence in detecting signs of sight-threatening DR and the desire to participate in community DR screening activities); and several specific management scenarios (the use of fluorescein angiography [FA], treatment order for patients with clinically significant macular oedema [CSME] and concurrent cataract or early proliferative diabetic retinopathy [PDR] [see copy of questionnaire in appendix 1 for detail]).

Responses were analysed using SPSS version 15.0 (SPSS, Chicago, IL, USA) with significance set at  $P < 0.05$  for all analyses. Relationships between categorical variables such as retinal specialty, location of practice, specialist experience and DR management practices were examined using Chi-squared analysis except when the expected frequencies of cells was less than five, in which case Fisher's exact tests were used. Multivariate logistic regression analyses were used to explore independently significant factors affecting ophthalmologists' adherence to NHMRC recommendations. All regression analyses were adjusted for retinal subspecialty, location of practice, country of medical training, duration of practice and percentage of patients with diabetes.

## RESULTS

The questionnaire was sent to 762 ophthalmologists of whom 11 (1.4%) were unable to be located because they had retired, died or moved practice. Of the remaining 751 eligible ophthalmologists, 480 (63.9%) completed and returned the questionnaire.

### Ophthalmologists characteristics

The professional characteristics of respondents are summarized in Table 1. The number of years practising as a specialist ophthalmologist among respondents ranged from 1 to 55 years (mean 17.0 years, SD 11.2 years, median 15 years) and the majority (82.2%) were trained in Australia. The average practice saw approximately 400 patients per month with the majority of practices (77.7%,  $n = 369$ ) reported to have  $\geq 5\%$  of their patient with diabetes. One hundred and one respondents (23.1%) indicated that they had a retinal subspecialty interest and 33.9% of respondents had practices in a rural location.

### Current practice and attitudes to DR management

A large majority of ophthalmologists (80%,  $n = 376$ ) always asked patients with diabetes about their blood glucose control although only 54.8% ( $n = 260$ ) and 41.3% ( $n = 194$ ) respondents sought this information for blood pressure and blood cholesterol control, respectively. Just over half of respondents 53.5% ( $n = 251$ ) consistently advised patients about the importance of risk factor control in delaying retinopathy. In multivariate logistic regression analyses, compared with others the retinal subspecialists were 2.28 (95% CI: 1.38–3.76,  $P = 0.001$ ) and 1.62 (95% CI: 1.01–2.61,  $P = 0.045$ ) times more likely to always review patients' blood pressure and blood cholesterol control, respectively; and 1.93 (95% CI:

1.18–3.16,  $P = 0.009$ ) times more likely to routinely advise their patients the importance of risk factor control in delaying retinopathy.

Regarding ophthalmologists' confidence in detecting clinical signs of sight-threatening DR, the majority of respondents (89.6%,  $n = 421$ ) reported being at least 'often confident' in detecting new blood vessels away from the optic disc (new vessels elsewhere,

**Table 1.** General characteristics of respondent Australian ophthalmologists and their practice details ( $n = 480$ )

Characteristics	Results (number [%])
Specialist practice duration (years)	Range: 1–55 years (mean = 17.0, SD = 11.2, median = 15)
≤5	86 (18.0%)
6–10	81 (16.9%)
11–15	77 (16.1%)
16–20	76 (15.9%)
21–25	50 (10.5%)
26–30	56 (11.7%)
>30	52 (10.9%)
Country of ophthalmic training	
Australia	393 ( $n = 82.2\%$ )
Other	85 ( $n = 17.8\%$ )
Practice size	Range: 1–3000 patients/month (mean = 428, SD = 286.3, median = 400)
≥1 rural practice location	160 ( $n = 33.9\%$ )
% of patients with diabetes	
<1%	165 (3.4%)
1–5%	90 (18.9%)
5–10%	155 (32.6%)
10–15%	113 (23.8%)
>15%	101 (21.3%)
Subspecialist interest	
None	152 (31.7%)
Vitreo-retinal	44 (9.2%)
Medical retinal	67 (14.0%)
Anterior segment	94 (19.6%)
Oculo-plastic	37 (7.7%)
Other	86 (17.9%)

NVE) and moderate thickening near the macula (87.2%,  $n = 408$ ). Retinal subspecialists were more likely to report a higher level of confidence for both NVE (95.5%,  $n = 106$  vs. 87.7%,  $n = 315$ ;  $P = 0.02$ ) and macular thickening (97.3%,  $n = 108$  vs. 84.2%,  $n = 308$ ;  $P = 0.01$ ) than others. After controlling for retinal subspecialty, clinician confidence for detecting macular thickening was 4.94 times greater in ophthalmologists with practice experience less than 15 years compared with those with >15 years practice duration (OR = 4.94, 95% CI: 2.52–9.68,  $P < 0.001$ ).

Overall, 49.3% ( $n = 236$ ) of respondents indicated a moderate or strong desire to more active participation in community DR screening, although retinal subspecialists were 2.37 times (95% CI: 1.45–3.88;  $P = 0.001$ ) more likely to report this desire than others. Around half of the ophthalmologists (53.4%,  $n = 253$ ) indicated that they routinely send recall notices to remind diabetic patients to return for eye examination.

## Hypothetical patient scenarios management

### Screening interval

Reported screening recommendations for the hypothetical diabetic patients of varying ages and diabetic control, without signs of DR on initial examination are shown in Table 2. As the duration of diabetes increased and glycaemic control worsened, there was a general trend for ophthalmologists to shorten the screening interval to within 1 year even if patients have no retinopathy signs. For the hypothetical 7-year-old child, only 38.3% ( $n = 181$ ) of ophthalmologists agreed with the 1997 NHMRC guidelines' recommendation to commence screening at puberty. Even though retinal subspecialists were significantly more likely to adhere to recommended practice than others (48.6%,  $n = 54$  vs. 35.2%,  $n = 127$ ,  $P = 0.011$ ),

**Table 2.** Percentage of responses for the screening interval of patients with DM of varying ages and diabetic control who have no signs of diabetic retinopathy on initial examination

Patient type	Refer elsewhere	Screening intervals			
		Begin screening in 5 years	Review in 2 years	Review in 1 year	Review in 6 months
7-year-old child with new type 1 DM	11.7	38.3 <sup>†</sup>	29.4	16.7	3.8
18-year-old with new type 1 DM	5.7	11.2	45.9 <sup>†</sup>	30.0	7.2
60-year-old with new diet-controlled DM	4.2	2.1	68.4 <sup>†</sup>	23.9	1.3
60-year-old with new oral hypoglycaemic-controlled DM	3.6	0.6	51.5 <sup>†</sup>	41.4	3.0
60-year-old with 10 years of well oral hypoglycaemic-controlled DM	3.6	0.4	44.5	49.6 <sup>†</sup>	1.9
60-year-old with 10 years of well insulin-controlled DM	2.9	0.6	29.9	61.3 <sup>†</sup>	5.3
60-year-old with 10 years of poor insulin-controlled DM	3.2	0.8	7.4	48.1 <sup>†</sup>	40.5

<sup>†</sup>Indicates the NHMRC-recommended practice. DM, diabetes mellitus; NHMRC, National Health and Medical Research Council.



**Table 3.** Percentage of responses for the frequency of fluorescein (FA) use in patients with varying signs of non-proliferative diabetic retinopathy (The NHMRC only recommends FA use in selected cases of severe non-proliferative diabetic retinopathy)

Presence of clinical signs	Frequency of performing FA				
	Never	Occasionally	Often	Always	Refer
No signs of diabetic retinopathy					
Overall	90.2	7.5	0.6	0.2	1.5
Retinal specialty					
Retinal	89.0	10.1	0.0	0.9	0.0
Non-retinal	90.5	6.7	0.8	0.0	1.9
Years in practice**					
≤15	95.0***	4.6*	0.0	0.0	0.4
>15	85.0***	10.6*	1.3	0.4	2.6
Mild non-proliferative diabetic retinopathy					
Overall	49.3	34.4	7.6	2.5	6.2
Retinal specialty					
Retinal	50.5	39.6	5.4	2.7	1.8
Non-retinal	48.9	32.8	8.3	2.5	7.5
Years in practice ***					
≤15	65.0***	28.4**	2.5***	0.4**	3.7*
>15	32.5***	40.8**	13.2***	4.8**	8.8*
Severe non-proliferative diabetic retinopathy					
Overall	4.5	20.0	25.1	31.4	19.1
Retinal specialty***					
Retinal	4.5	26.1	27.0	39.6*	2.7***
Non-retinal	4.4	18.1	24.4	28.9*	24.2***
Years in practice ***					
≤15	6.6*	28.8***	25.9	23.5***	15.2*
>15	2.2*	10.5***	24.1	39.9***	23.2*

\* $P < 0.05$ , \*\* $P \leq 0.01$ , \*\*\* $P \leq 0.001$ . FA, fluorescein angiography; NHMRC, National Health and Medical Research Council.

51.4% ( $n = 57$ ) of them commenced screening of the pre-pubertal child earlier than recommended by the NHMRC.

### Use of fluorescein angiography

Responses to the patient scenario regarding the use of FA in patients with varying retinopathy severity are summarized in Table 3. Almost all ophthalmologists (90.2%,  $n = 422$ ) indicated they would not use FA when there were no signs of retinopathy, although 44.5% ( $n = 210$ ) would at least occasionally use FA for patients with mild non-proliferative diabetic retinopathy (NPDR), contrary to the 1997 NHMRC guidelines. There was no significant difference in FA use among respondents until the hypothetical patient had severe NPDR, where retinal subspecialists were 1.72 times (95% CI: 1.08–2.73,  $P = 0.022$ ) more likely to perform FA on such patients than others. In all degrees of DR, there was a consistent trend of more frequent use of FA among ophthalmologists who received their specialty training in the earlier years. In particular, ophthalmologists with >15 years practice duration were 3.12 (95% CI: 1.55–6.27,  $P = 0.001$ ) and 3.74 (95% CI: 2.53–5.53,  $P < 0.001$ ) times more likely to perform FA in patients with none or mild NPDR, respec-

tively; and 2.23 times (95% CI: 1.48–3.37,  $P < 0.001$ ) more likely to always perform FA in patients with severe NPDR than those with shorter practice duration.

### Concurrent CSME with cataract or early PDR

Responding to a complex case where a patient with coexistent CSME and cataract that would make the former difficult to treat, 26% ( $n = 95$ ) of ophthalmologists indicated that they would refer such a patient to retinal subspecialist for management. Those with rural practice were less likely to refer than metropolitan-only ophthalmologists (13.9%,  $n = 17$  vs. 32.2%,  $n = 77$ ,  $P < 0.001$ ). Excluding those who refer, most ophthalmologists (94.2%,  $n = 356$ ) would treat the CSME first. Only 5.8% ( $n = 22$ ) were contrary to the NHMRC guidelines and would delay macular laser therapy until cataract surgery had been performed. From the multivariate logistic regression analysis, ophthalmologists with duration of practice >15 years were 7.8 times (95% CI: 2.23–27.36,  $P < 0.001$ ) more likely to perform cataract surgery first. There was no significant difference in the order of treatment between retinal subspecialists and others.

**Table 4.** Percentage of responses for the management of patients with varying signs of retinopathy

Presence of clinical signs	Follow-up interval/management					
	Refer	Review in 2 years	Review in 1 year	Review in 6 months	Review in 3 months	Angiogram $\pm$ laser
Mild NPDR	3.8	13.0	67.0	14.3	1.7	0.2
Mod NPDR	11.5	0.4	18.7	49.1	10.7	9.6 <sup>†</sup>
Severe NPDR	17.4	0.0	3.4	17.4	24.1	37.7 <sup>†</sup>

<sup>†</sup>Ophthalmologists with >15 years practice experience were again more likely to perform fluorescein angiography and/or photocoagulation than others (16.5%,  $n = 38$  vs. 3.3%,  $n = 8$ ;  $P < 0.001$  for moderate NPDR, 44.6%,  $n = 103$  vs. 31.3%,  $n = 77$ ;  $P < 0.001$  for severe NPDR). NPDR, non-proliferative diabetic retinopathy.

**Table 5.** Comparison of respondents' attitude and practices in diabetic retinopathy management recorded during the baseline, first follow-up and current survey<sup>5,6</sup>

Questions	Percentage of response		
	Baseline (1997)	First follow up (1998)	Current
Often or always advise about importance of risk factor control	96.8	97.3	92.6
Use of recall notices	16.7	22.4	53.4
Often to always feel confident in detecting NVE	94.1	93.5	89.6
Often to always feel confident in detecting moderate retinal thickening near the macular	80.2	79.1	87.2
Moderate to strong perceived need for further education in diabetic retinopathy	58.9	52.0	46.9
Moderate to strong desire to participate in community diabetic retinopathy screening	60.2	56.4	49.3

NVE, new vessels elsewhere.

With the second complex case, a patient with CSME and early PDR, 45.9% ( $n = 169$ ) of ophthalmologists would refer the patient to retinal subspecialists for further management. Those with rural practice were again less likely to refer than metropolitan-only ophthalmologists (32.8%,  $n = 40$  vs. 51.9%,  $n = 125$ ,  $P = 0.001$ ). Excluding those who refer, 1.9% ( $n = 9$ ) of all surveyed ophthalmologists reported performing pan-retinal photocoagulation first, 55.6% ( $n = 266$ ) would perform macular photocoagulation first, and 6.5% ( $n = 31$ ) would perform both procedures together. The likelihood of adhering to NHMRC's recommendation of performing focal laser first in such patient did not differ by subspecialty, experience, practice location or the country of training.

## Management of retinopathy

The responses for the management of patients with varying severity of retinopathy are shown in Table 4. The 1997 NHMRC recommended follow-up intervals for patients with signs of retinopathy (annual review for patients with isolated peripheral micro-aneurysm and three to six monthly reviews for patients with moderate to severe retinopathy) were followed by the majority (>80%) of ophthalmologists. There was no significant difference in follow-up practice between

retinal subspecialists and others. In the patients with moderate and severe NPDR, ophthalmologists with >15 years practice experience were again more likely to perform FA and/or photocoagulation than others (16.5%,  $n = 38$  vs. 3.3%  $n = 8$ ;  $P < 0.001$  for moderate NPDR, 44.6%  $n = 103$  vs. 31.3%  $n = 77$ ;  $P < 0.001$  for severe NPDR).

## Compared with the previous survey

To evaluate the long-term effects of the 1997 DR guidelines on clinician's practice, the published figures from previous surveys performed by CERA were compared with results of the current study (see Tables 5, 6). Possible improvements towards recommended practice included reduction in the proportion of ophthalmologists using FA in patients with mild NPDR and performing cataract surgery prior to treating CSME. Other positive changes included a greater confidence in detecting macular oedema and the increasing use of patient reminder notices. Reminders for patients has been shown to improve compliance to clinical guideline's recommendations.<sup>9</sup>

In contrast to these improvements, our findings also suggest that there were some negative changes in DR management by Australian ophthalmologists. For example, there was a reduction in the desire to participate in community DR screening and in the

**Table 6.** Comparison of percentages of ophthalmologists whose responses to the hypothetical scenarios were contrary to the NHMRC guideline recommendations<sup>5,6</sup>

Scenario	Percentage practice against recommended practice		
	Baseline (1997)	First follow up (1998)	Current
Diabetic retinopathy screening for a 7-year-old child	53.0	46.5	49.9
Fluorescein angiogram for patient with nil retinopathy	7.6	10.6	8.3
Fluorescein angiogram for patient with mild NPDR	53.3	52.1	44.5
Recommended treatment order for patient with CSME and cataract	15.9	11.9	4.6
Recommended treatment order for patient with CSME and PDR	10.3	7.6	8.4

CSME, clinically significant macular oedema; NHMRC, National Health and Medical Research Council; NPDR, non-proliferative diabetic retinopathy; PDR, proliferative diabetic retinopathy.

proportion of ophthalmologists who consistently advise patients regarding the importance of risk factor control.

## DISCUSSION

We found the majority of ophthalmologists adhered to most of the 1997 NHMRC DR management guidelines, but there were several areas of difference. These included: (i) frequency of advice regarding DR risk factor control (including blood pressure and serum cholesterol); (ii) when to screen for retinopathy in the pre-pubertal patients with diabetes; and (iii) use of FA in patients with no or early DR.

In keeping with the increasing trend of subspecialization within ophthalmology,<sup>10,11</sup> we found that many ophthalmologists referred complex DR cases to retinal specialists for further management (up to 45.9%). Rural ophthalmologists were however significantly less likely to refer, perhaps because of logistic difficulties with follow up as a result of geographical separation. Retinal subspecialists were more likely to follow the NHMRC guidelines, had a greater desire to participate in screening and had more confidence detecting sight-threatening retinopathy than others. Although subspecialization may introduce problems in the planning and organization of clinical services,<sup>10</sup> some found better clinical outcomes when certain conditions, such as retinal detachment and corneal grafting, were managed by subspecialists rather than generalists.<sup>10,11</sup> No study, however, has compared clinical outcomes from the management of DR by retinal subspecialists with those by generalists.

We found that ophthalmologists with longer practice duration (>15 years) were more likely to differ from the NHMRC recommendations in several aspects of DR management. They were up to 3.7 times more likely to use FA in patients with mild NPDR and were nearly eight times more likely to treat cataract first prior to macular laser for patients with CSME and cataract. This discrepancy may

reflect the evolution in recommended practice that has occurred over time. Ophthalmologists who were qualified earlier may have received teaching that was different from the current guidelines. This group of ophthalmologists may benefit from additional targeted continual medical education activities that are more effective in encouraging a shift towards current best evidence-based practices.<sup>12</sup>

In recent times treatment for DR and maculopathy using intravitreal injection of triamcinolone (IVTA) and anti-angiogenic agents has increased.<sup>13</sup> Anecdotally, a number of ophthalmologists noted that they would perform IVTA at the time of cataract surgery for the hypothetical patient with both CSME and cataract. Several respondents also commented that they would combine IVTA or anti-angiogenic drugs with laser therapy for the patient with CSME and PDR. The revised 2008 guidelines suggest that IVTA may be considered for selected cases where macular oedema persists after focal/grid laser treatment.<sup>8</sup>

Because the study design and the questionnaire used in the current study was similar to previous surveys by CERA, it was possible to compare results between different survey time-points to identify possible trends in DR management practice. However, it is noted that the current study had a lower response rate than previous CERA surveys (64% vs. 82%), increasing the susceptibility of this study to response bias. Nevertheless, the comparisons identified a few modest changes in DR management practices among Australian ophthalmologists towards NHMRC recommendations, in particular, regarding FA use in patients with mild NPDR and the treatment order for concurrent cataract and CSME. On the other hand, the consistency in advising about risk factors control and the interest in community DR screening may have declined. Substantial resources are invested in the development and revision of clinical guidelines such as that produced by NHMRC for DR management.<sup>14</sup> It is therefore important to consider the cost-effectiveness of such undertaking. Previous studies have demonstrated that the process of merely provid-

ing information through passive dissemination of the clinical guidelines alone without appropriate implementation strategies is rarely sufficient to stimulate corresponding changes in practice.<sup>15</sup> Hence, other avenues of communication that supplement or surpass clinical guidelines in producing change in specialist practice should be further explored.

In conclusion, although the overall adherence to the guidelines by Australian ophthalmologists was good, we found several areas for improvement. Ophthalmologists with longer practice duration were more likely to employ some DR management practices differing from that recommended. Retinal subspecialists, however, were more likely to follow the guidelines and many other ophthalmologists prefer to refer complex diabetic cases to them for further management.

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## Original Article

## Diabetic retinopathy management by Australian optometrists

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## ABSTRACT

**Background:** To survey the current diabetic retinopathy screening and management practices of Australian optometrists following the release of the 1997 National Health Medical Research Council Diabetic Retinopathy Management Guidelines.

**Design:** Cross-sectional national survey, primary care setting.

**Participants:** 1000 Australian optometrists across different states.

**Methods:** A self-administered questionnaire was sent to 1000 optometrists across all states during 2007/2008.

**Main outcome measures:** Use of retinal camera, screening practices/attitudes and behaviour in diabetic retinopathy management.

**Results:** 568 optometrists (57%) responded to the survey. Patients' unpreparedness to drive post dilation (51%) and the fear of angle closure glaucoma (13%) were the two main barriers to optometrists not performing dilated ophthalmoscopy. Those who had strong desire to screen for diabetic retinopathy were more likely to use a retinal camera ( $p < 0.005$ ). Use of a retinal camera was significantly associated with an increased confidence in detecting clinical signs of diabetic retinopathy including macular oedema ( $P < 0.001$ ). Optometrists who read the

guidelines at least once were 2.5-times ( $P < 0.001$ ) more likely to have confidence in detecting macular oedema than those who had never read the guidelines. Although they may be confident in diagnosis, and may use retinal cameras for screening, nearly 60% of optometrists would not refer patients with macular oedema to an ophthalmologist.

**Conclusions:** Despite their self-reported desire for involvement in diabetic retinopathy, the management of macular oedema by Australian optometrists needs improvement. The use of retinal cameras and promotion of the 2008 NHMRC guidelines should be encouraged to improve overall optometric diabetic retinopathy management, particularly with macular oedema.

**Key words:** diabetes, diabetic retinopathy, screening, survey.

## INTRODUCTION

The prevalence of diabetes mellitus is growing rapidly worldwide.<sup>1</sup> In 2000, there were approximately 941 000 Australians living with diabetes, and it is estimated that by 2030, this will rise to 1.6 million.<sup>1</sup> Diabetic retinopathy (DR) occurs in 25% of patients with diabetes in Australia.<sup>2</sup> As 98% of visual impairment secondary to DR can be prevented by timely treatment, early detection is crucial.<sup>3</sup>

As the primary eye care providers, the optometrists and general practitioners play an enormous

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role in DR screening in the community. As part of routine DR screening, the National Health and Medical Research Council (NHMRC) guidelines<sup>4</sup> recommended that all examiners should assess patients' best-corrected visual acuity and perform dilated fundus examination at time of diagnosis of diabetes. Alternately, the dilated fundus examination may be replaced by retinal photography. Additional information such as HbA1c (glycosylated haemoglobin), blood pressure profile, lipid profile, smoking status and other diabetes-related complications may also help in determining the urgency for referrals.

Australian optometrists have previously been surveyed in 1999 and 2001<sup>5,6</sup> following the release of the original 1997 NHMRC guidelines on DR management.<sup>7</sup> A revised version of these guidelines was released in late 2008.<sup>4</sup> However, to date no published studies have examined the long-term impact of these guidelines on DR screening and management practices among Australian optometrists.

Our aim was to identify any changes in DR screening and management practices that have occurred over the last decade following the release of these national guidelines. This will provide information that will guide the implementation of the revised guidelines, as well as establishing updated data for future evaluation.

## METHODS

We conducted a cross-sectional survey of currently practising Australian optometrists. A random sample of 1000 optometrists was selected from the Optometrists Association of Australia membership database (4414 members). A self-administered two-page questionnaire, an information pamphlet about the objectives of this study and a postage-paid return envelope were mailed to each selected optometrist in November 2007. A repeat mail-out of surveys to non-respondents was conducted after 3 months to maximize responses. The University of Western Australia Human Research Ethics Committee approved this study.

The questionnaire used for this study was adapted from two previous surveys conducted by McCarty *et al.*<sup>5,6</sup> to allow temporal comparison regarding DR management practices by Australian optometrists. The survey instrument comprised questions relating to general professional and practice details, and DR screening attitudes and practices (e.g. perceived barriers and estimated frequency of performing dilated funduscopy on diabetic patients, confidence in detecting sight-threatening DR, desire to participate in community screening and perceived need for further education on DR).

Optometrists were surveyed about their management practices using 12 hypothetical clinical scenarios. The first seven scenarios involved patients of different ages (7, 18 and 60 years of age), varying diabetic treatment (diet alone, oral hypoglycaemic agent or insulin) and who had no DR detected at their first visit. The last five scenarios focused upon DR management following the detection of microaneurysms, retinal haemorrhages, new vessels formation and macular oedema. Optometrists were given five choices of performing dilated funduscopy in less than 6 months, 1 year, 2 years, 5 years or prompt referral to an ophthalmologist.

All participants remained anonymous throughout data collection and analyses. Responses were analysed using Stata 10.0 (StataCorp, College Station, TX, USA) with significance set at  $P < 0.05$  for all analyses. Descriptive statistics were calculated for all continuous variables. Relationships between categorical variables were explored using Pearson  $\chi^2$ -tests. Multivariate logistic regression models were used where appropriate to explore outcomes of interest (such as the use of a retinal camera and confidence of detecting DR signs and diabetic macular oedema) while controlling for possible confounding factors of practice location, place of training and years of practice.

## RESULTS

A total of 568 (57%) optometrists currently practising in Australia responded to the survey. Demographic characteristics of the respondent optometrists are shown in Table 1. Our sample size was 13% of the total optometrists practising in Australia (total optometrists = 4414), and the percentage of state and urban/rural distribution of the respondent optometrists was reasonably comparable to the data published by the Australian Institute of Health and Welfare (AIHW) in 2006.<sup>8</sup> More than 80% reported receiving a copy of the 1997 NHMRC guideline, and only 65% reported having read them at least once.

Of the ophthalmic equipment used by optometrists to examine patients with diabetes, the direct ophthalmoscope was most frequently used (72%), followed by slit-lamp biomicroscopy (65%), binocular indirect ophthalmoscope (56%) and retinal camera (51%). Almost 15% of optometrists never performed direct ophthalmoscopy whereas 55% of optometrists used a retinal camera in their practices on more than half of their diabetic patients.

Table 2 shows the perceived barriers to optometrists not performing dilated ophthalmoscopy. Patients' unpreparedness to drive (51%) and a fear of precipitating angle closure glaucoma (13%) post dilation were the two leading reported 'moderate' to 'major' barriers. Only a small number of optometrists

**Table 1.** Demographics of the optometrists responding to a survey on diabetic retinopathy screening

	Total number (%)
State or Territory of practice – 566	
New South Wales	195 (34%)
Victoria	160 (28%)
Queensland	97 (17%)
Western Australia	44 (7%)
South Australia	42 (7%)
Tasmania	20 (4%)
ACT	7 (1%)
Northern Territory	1 (<1%)
Number of years of practice	
0–10	42 (7%)
11–20	169 (30%)
21–30	260 (46%)
>30	97 (17%)
Location of practices	
Metropolitan	359 (64.1%)
Rural	170 (30.4%)
Metropolitan and rural	31 (5.5%)
Location of training	
Australia	520 (92%)
UK	25 (4%)
South Africa	9 (2%)
New Zealand	8 (1%)
USA	2 (<1%)
Canada	1 (<1%)

reported a lack of confidence in detecting changes (2%) and uncertainty about DR management (1%) as moderate to major barriers to performing dilated funduscopy.

Table 3 summarizes reported current practices, examinations procedures and routine enquiry of risk factors by optometrists. About 90% of optometrists reported either ‘often’ or ‘almost always’ performing dilated funduscopy on patients with known diabetes, and only 23% would routinely perform dilated funduscopy on patients without any history of diabetes or glaucoma. Two-thirds always questioned about a positive diagnosis of diabetes in patients older than 40 years. As part of routine follow up for patients with diabetes, 95% of optometrists ‘often’ or ‘almost always’ enquired about blood glucose level, as well as factors such as assessment of blood pressure, cholesterol level, smoking status and importance of risk factors control to prevent diabetes complications (Table 3).

Almost all optometrists reported being ‘often’ or ‘always’ confident in detecting microaneurysms (93%) and retinal haemorrhages (97%), but fewer were confident in detecting new vessel formation (85%). More than 50% of the optometrists were ‘often’ or ‘always’ unsure in detecting macular oedema.

**Table 2.** Barriers to optometrists performing dilated funduscopy

Barriers	Not a barrier	Minor barrier	Moderate barrier	Strong barrier
Patients’ unpreparedness to drive	68 (12%)	205 (37%)	179 (32%)	107 (19%)
Worry of angle closure glaucoma	305 (55%)	185 (33%)	48 (9%)	22 (4%)
Time consuming	297 (53%)	195 (35%)	61 (11%)	9 (2%)
Lack of dilating drops	539 (97%)	9 (2%)	2 (<1%)	8 (1%)
Lack of ophthalmoscopes	545 (98%)	3 (1%)	3 (1%)	6 (1%)
Lack of confidence in detecting changes	468 (84%)	76 (14%)	11 (2%)	1 (<1%)
Unsure of diabetic retinopathy management	514 (92%)	37 (7%)	6 (1%)	1 (<1%)

**Table 3.** Current optometrists’ management and attitudes to diabetes and diabetic retinopathy

Screening questions and examinations	Almost never	Sometimes	Half the time	Often	Almost always
On patients >40 years					
1 Routine questioning about diagnosis of diabetes	20 (4%)	56 (10%)	21 (4%)	80 (14%)	389 (69%)
2 Routine dilated funduscopy without history of diabetes or glaucoma	102 (18%)	258 (46%)	73 (13%)	56 (10%)	74 (13%)
3 Routine of dilated funduscopy with history of diabetes	13 (2%)	27 (5%)	22 (4%)	58 (10%)	448 (79%)
Frequency of risk factors enquiries					
Blood sugar control	2 (<1%)	3 (<1%)	21 (4%)	95 (17%)	446 (79%)
Blood pressure control	10 (2%)	15 (3%)	77 (14%)	185 (33%)	279 (49%)
Blood cholesterol control	14 (3%)	53 (9%)	121 (21%)	167 (30%)	211 (37%)
Smoking status	48 (9%)	116 (21%)	161 (28%)	140 (25%)	102 (18%)
Advice regarding complications	11 (2%)	33 (6%)	98 (17%)	221 (39%)	202 (36%)



**Table 4.** Optometrists' management of hypothetical clinical scenarios and specific signs of DR

Case scenarios	Referral to ophthalmologists	Review in 5 years	Review in 2 years	Review in 1 year	Review in <6 months
If no signs of DR at baseline examination					
7-yo – newly diagnosed diabetic	95 (17%)	63 (11%) <sup>†</sup>	125 (22%)	183 (33%)	96 (17%)
18-yo – newly diagnosed with DM	40 (7%)	16 (3%)	141 (25%) <sup>†</sup>	255 (45%)	113 (20%)
60-yo with good HbA1c control – diet alone	5 (1%)	1 (<1%)	211 (37%) <sup>†</sup>	290 (51%)	58 (10%)
60-yo, 10-year diabetes, commenced on OHA	9 (2%)	0 (0%)	86 (15%) <sup>†</sup>	374 (66%)	98 (17%)
60-yo, 10-year diabetes with good HbA1c on OHA	10 (2%)	1 (<1%)	72 (13%) <sup>†</sup>	417 (74%)	65 (12%)
60-yo, 10-year diabetes with good HbA1c on insulin	21 (4%)	0 (0%)	31 (6%) <sup>†</sup>	409 (72%)	105 (19%)
60-yo, poorly controlled HbA1c despite insulin	79 (14%)	0 (0%)	2 (<1%)	127 (22%) <sup>†</sup>	360 (63%)
DR signs					
Occasional microaneurysms on peripheries	43 (8%)	14 (3%)	297 (53%)	167 (30%) <sup>†</sup>	44 (8%)
Macular oedema (not clinically significant)	234 (41%) <sup>†</sup>	6 (1%)	43 (8%)	138 (25%)	139 (25%)
Peripheral microaneurysms and retinal haemorrhages	224 (40%)	0 (0%)	81 (14%)	169 (30%)	93 (16%) <sup>†</sup>
Extensive microaneurysms, retinal haemorrhages and occasional cotton wool spots all located peripherally	509 (90%) <sup>†</sup>	0 (0%)	4 (1%)	18 (3%)	36 (6%)
New vessel formation	557 (98%) <sup>†</sup>	0 (0%)	0 (0%)	1 (<1%)	10 (2%)

<sup>†</sup>Recommended time frame suggested by National Health and Medical Research Council guidelines in 1997. DM, diabetes mellitus; DR, diabetic retinopathy; HbA1c, glycosylated haemoglobin; OHA, oral hypoglycaemic agents; yo, year-old.

Most optometrists (95%) used a recall system to follow up patients with diabetes for examination. However, only half reported that more than 70% of their patients would return to see them within the suggested time frame. When patients were referred to ophthalmologists, the majority (83%) of referring optometrists reported that more than 70% of their patients would see their ophthalmologist within the suggested time frame. The percentage of optometrists expressing 'moderate' to 'strong' desire to screen for, and receive further education regarding DR was 78% and 72%, respectively.

### Changes in reported management since 1999<sup>5</sup>

The percentage of optometrists performing dilated funduscopy on diabetic patients has increased significantly from 75% in 1999 to 89% in 2009 ( $P < 0.001$ ). In addition, the confidence in detecting sight-threatening DR changes (new vessels elsewhere and macular oedema) improved significantly from 1999 to 2009 (new vessels elsewhere: 75–85%,  $P < 0.01$ ; macular oedema: 33–47%,  $P < 0.001$ ). Significantly, more optometrists reported using a recall system in 2009 (95%) compared with 1999 (83%). From 1999 to 2009, there were no significant changes in the potential perceived barriers such as fear of inducing angle closure glaucoma post dilation (1999: 17%; 2009: 13%), lack of confidence in detecting DR changes (1999: 4%; 2009: 2%), uncertainty about DR management (1999: 2%; 2009: 1%) and the desire to screen for DR (1999: 84%; 2009: 78%). In contrast, there was significantly less desire for further educa-

tion about DR diagnosis and management from 1999 to 2009 (84% to 72%,  $P < 0.0001$ ).

### Responses to the hypothetical clinical scenarios (Table 4)

Only 11% of optometrists reported that they would perform dilated funduscopy on a 7-year-old child newly diagnosed with diabetes in 5 years, and 17% would refer this child to an ophthalmologist. Optometrists would still recommend a 12-month examination for diabetic patients with good glycaemic control with no signs of DR compared with the 2-year follow up recommended by the NHMRC guidelines (Table 3). Nonetheless, the overall percentage of optometrists following the NHMRC-recommended management practices (dilated funduscopy within 1 or 2 years of diagnosis, or referral to an ophthalmologist) was greater than observed in 1999. In 2009, the majority of optometrists reported that they would refer patients with severe non-proliferative DR (NPDR) (90%) and proliferative DR (PDR) (98%) to an ophthalmologist. However, only 42% would refer patients with macular oedema to an ophthalmologist for prompt investigation and treatment.

From multivariate logistic regression analyses, optometrists who had a strong desire to screen for DR were almost twice as likely to 'often' or 'almost always' use a retinal camera to examine patients with diabetes after controlling for previous training location, duration and location of current practice (OR = 1.98, 95% CI = 1.27–3.10,  $P < 0.005$ ).

When controlled for reading the guidelines, previous training location, duration and location of practice, optometrists who 'often' and 'always' used a retinal camera were more confident in detecting retinal diabetic changes such as microaneurysms (OR = 5.29, 95% CI = 2.22–12.40,  $P < 0.001$ ), new vessels formation elsewhere (OR = 4.62, 95% CI = 2.56–8.34,  $P < 0.001$ ) and macular oedema (OR = 2.49, 95% CI = 1.51–4.12,  $P < 0.001$ ).

Reading the guidelines at least once was also associated with increased confidence in detecting macular oedema (OR = 2.49, 95% CI = 1.51–4.12,  $P < 0.001$ ). However reading the guidelines did not improve referrals for patients with macular oedema (OR = 1.04, 95% CI = 0.65–1.65,  $P = 0.88$ ). Likewise confidence in detecting macular oedema after controlling for other factors such as previous training location, duration and location of practice and use of a retinal camera was not associated with optometric referrals of patients with macular oedema to an ophthalmologist (OR = 0.99, 95% CI = 0.71–1.39,  $P = 0.97$ ).

## DISCUSSION

Our results indicate that DR management practices of Australian optometrists have improved since the release of NHMRC guidelines in 1997.<sup>7</sup> Compared with the two national surveys conducted in 1999 and 2001,<sup>5,6</sup> more optometrists now perform dilated funduscopy on diabetic patients, use recall notices and had greater confidence in detecting and managing DR changes in their patients. Additionally, nearly 80% of optometrists had 'moderate' to 'strong' desire to screen for DR. This could significantly reduce the waiting period of diabetic patients to see an ophthalmologist in the public setting and may triage the urgency of ophthalmic review by severity, especially for patients with sight-threatening DR. We also found an approximate 10% rise in the use of recall notices over the last decade. This helps to ensure regular eye screening of patients, as a patient reminder system was reported to be an effective way of enforcing and increasing the patients' adherence to clinical guidelines.<sup>9</sup>

Both the 1997 and 2008 NHMRC guidelines<sup>6,7</sup> recommend that screening of diabetic children should start at the time of puberty, with the screening interval determined by the clinical findings. Those with moderate to severe NPDR, PDR or macular oedema warrant prompt referrals to an ophthalmologist. We found that optometrists generally reviewed diabetic patients with no signs of DR more frequently than recommended.<sup>7</sup> The optometrists should be encouraged to read the guidelines more frequently in order to review the patients with diabetes in an

appropriate time frame to reduce their unnecessary financial burden.

The responses we obtained regarding the management of diabetic macular oedema by Australian optometrists were of concern. More than 50% of optometrists reported that they lacked confidence in detecting macular oedema and only 40% would refer patients with macular oedema to an ophthalmologist.

Although both the use of a retinal camera and reading the guidelines were significantly associated with increased confidence in detecting macular oedema, they were not associated with appropriate referral of patients with macular oedema to an ophthalmologist. Confidence in detecting macular oedema was also not associated with referrals to an ophthalmologist.

In other words, the optometrists were not likely to refer patients with macular oedema to an ophthalmologist despite having read the guidelines, being confident in detecting macular oedema and using a retinal camera. Given macular oedema is a major cause of significant visual impairment, optometrists need to improve their management (confidence to detect and referrals) of this condition to ensure prompt laser treatment for patients with diabetic maculopathy. Although early stages of macular oedema may be difficult to detect without indirect ophthalmoscopy, any reduction in visual acuity should raise suspicion and prompt a referral.

Concern about use of dilating drops inducing angle closure glaucoma seems unwarranted as it is a rare event (1 in 20 000).<sup>10</sup> Promoting the use of non-mydratic fundus cameras may help. We found there was a strong association between the frequency of retinal camera use and the desire to screen, as well as confidence in detecting DR changes. Others have found non-mydratic retinal camera fundus photography yielded a reasonable sensitivity (95%) and specificity (99%).<sup>11</sup>

The present study provides an overview of DR management by Australian optometrists, which has improved over the last decade following the release of 1997 NHMRC guideline.<sup>7</sup> Given that macular oedema causes significant visual impairment in patients with diabetes, further education about the detection and referral of subjects with macular oedema is important. The use of retinal cameras and promotion of the new 2008 NHMRC guidelines<sup>7</sup> should be encouraged to improve the overall optometric DR management and reduce the incidence of this preventable blinding disease in the future. A further survey may help assess the impact of the new 2008 NHMRC guidelines, especially the management of diabetic macular oedema by Australian optometrists.

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**Clark A, Ng JQ, Morlet N, Mahendran P, Tropiano E, Spilsbury K, Preen DB, Semmens JB. Quality of life after postoperative endophthalmitis. *Clinical and Experimental Ophthalmology* 2008; 36(6):526-531.**

# Original Article

## Quality of life after postoperative endophthalmitis

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### ABSTRACT

**Purpose:** The aim of this study is to determine if postoperative endophthalmitis adversely affects quality of life after cataract surgery.

**Methods:** We compared quality of life in patients who developed endophthalmitis after cataract surgery between 1 January and 31 December 2003 with those who had uncomplicated surgery. The National Eye Institute VFQ-25 (VFQ-25) and EuroQol EQ-5D (EQ-5D) questionnaires and time trade-off utility scores were used to compare self-perceived general health and vision-related quality of life between groups. Linear regression was used to model differences between groups after adjusting for age, gender and visual acuity in the better eye.

**Results:** Nineteen postoperative endophthalmitis cases were compared with 30 who had uncomplicated cataract surgery. Following surgery the mean composite VFQ-25 score was 13.5% (95% confidence interval [CI]: 6.0–26.4,  $P < 0.01$ ) lower in endophthalmitis cases. Endophthalmitis patients reported significantly lower ( $P < 0.05$ ) general vision, near vision, peripheral vision, mental health and role difficulties subscales scores after adjusting for age, sex and visual acuity. No significant differences were found in other subscales. Mean time trade-off utility and all EQ-5D scores were similar except for mobility (95% CI: 0.04–0.68,  $P < 0.05$ ).

**Conclusions:** Endophthalmitis after cataract surgery negatively impacts on self-perceived vision-related quality of life, resulting in poorer psychological well-being and ability to maintain a role in daily life.

**Key words:** adverse event, cataract surgery, postoperative endophthalmitis, quality of life.

### BACKGROUND

Cataract extraction surgery is the most commonly performed operation in the developed world.<sup>1,2</sup> Although sight-threatening complications are uncommon, endophthalmitis occurs in approximately one out of every 500 cataract operations performed in Australia.<sup>1,3</sup> Despite improvements in prevention and treatment, endophthalmitis remains a serious complication, often resulting in severe long-term visual impairment and significant morbidity.<sup>3,4</sup>

Visual acuity (VA) is the most commonly reported outcome measure in studies investigating postoperative endophthalmitis.<sup>3,4</sup> However, VA is unable to describe the impact of endophthalmitis upon a patient's perceived quality of life (QOL) where social interaction, mental health, dependency and functional ability likely play an important role. Visual impairment has been repeatedly reported to limit social interaction, psychological well-being and independence, and increases morbidity resulting in a poorer QOL.<sup>5–8</sup> Although it is generally assumed that postoperative endophthalmitis reduces QOL owing to its detrimental effects on visual outcomes, this has not yet been empirically demonstrated.

There is a growing trend in ophthalmology towards the use of standardized health-related QOL measures to support clinical decision making since they allow the impact of eye diseases and treatment outcomes to be quantified from predominantly values-based measures.<sup>9</sup> In the case of postoperative endophthalmitis, quantification of the personal burden imposed is an important consideration in determining its overall cost. Given the enormous cost associated with routine chemoprophylaxis to prevent relatively few postoperative endophthalmitis cases,<sup>10</sup> QOL analysis is an essential consideration to properly assess and justify the costs and benefits of alternative chemoprophylaxis regimes.

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We assessed the impact of postoperative endophthalmitis on patients' self-reported perceptions of vision and health-related QOL measured using the National Eye Institute's VFQ-25 (VFQ-25)<sup>11</sup> questionnaire, the EuroQol EQ-5D (EQ-5D)<sup>12</sup> questionnaire and time trade-off (TTO) utility values.<sup>13</sup>

## METHODS

Self-perceived health and vision-related quality of life (VRQOL) was compared between patients who developed endophthalmitis after cataract surgery (cases) with those who had uncomplicated cataract surgery ('controls').

### Study population

Patients who had postoperative endophthalmitis were recruited prospectively between 1 January and 31 December 2003 from three teaching hospitals in Western Australia where the vast majority of cases of endophthalmitis in the State are treated.<sup>3</sup> They were defined as patients who had a clinical diagnosis of postoperative endophthalmitis within one month following cataract surgery. The associated cataract operation was not necessarily performed at the endophthalmitis-treating hospital. Each eligible patient was approached and invited to participate in the study. Of the 30 potential cases of postoperative endophthalmitis identified, 19 (63%) consented to participate.

Controls were randomly selected from all cataract operations performed in two of the teaching hospitals over the study period. Fifty-one patients were approached to participate in the study, of which 30 (59%) consented to do so.

### Tools

The VFQ-25 measures the influence of visual disabilities and visual symptoms on generic health domains such as emotional well-being and social functioning, and task-oriented domains related to visual functioning. It consists of 12 subscales: general health, general vision, near activities, distance vision, driving, peripheral vision, colour vision, ocular pain, role limitation, dependency, social function and mental health.<sup>11</sup> For each subscale, there is choice of five possible answers. The responses to questions within each subscale are converted to a score out of 100, with zero representing the worst possible score. A composite score provides an average of all 12 subscales.

The EQ-5D measures generic health-related QOL across five domains: mobility, self-care, usual activities, pain/discomfort and anxiety/depression.<sup>12</sup> Each question has three possible answers (1 = 'no problem', 2 = 'some problem' and 3 = 'severe problem'). A summary score is derived from conversion of the five scores, where 1 is the maximum score and indicates best health status. A visual analogue scale is also included in this instrument in which general health status is a score out of 100.

Utility values for cases and controls were calculated using the TTO method. A score is generated by asking participants to state the maximum number of years of their remaining life they would be willing to give up or 'trade' to receive perfect vision. This fraction is then subtracted from 1.0 to give a utility value between 1.0 and 0, where 1.0 represents a perfect health state and 0 is death.

### Data collection

The VFQ-25 and EQ-5D questionnaires and the TTO utility question were administered to cases via interview and were self-administered by the control group. To avoid bias in participant responses, interview questions were asked verbatim according to the written instructions provided to controls. Questionnaires were administered to cases and controls 12 months following cataract surgery to ensure results were more reflective of the long-term impact of endophthalmitis rather than the acute effect of the disease. Clinical information was obtained directly from participants and through review of the hospital medical record. Details recorded included age, sex, best-corrected VA, comorbidity (recorded as a Charlson Index of Comorbidity<sup>14</sup>) and level of function in activities of daily living (recorded using the Modified Barthel Index<sup>15</sup>). Best-corrected VA was that recorded in the medical record nearest the time of data collection.

### Statistical analysis

Analysis was performed using Stata version 9.2 (Statacorp, College Station, TX, USA). Univariate analysis of categorical data for both cases and controls were compared using Fisher's exact test, and for continuous variables using independent *t*-test. The groups were further divided based on the best-corrected VA; those with a VA < 6/12 in their best eye were regarded as vision impaired, whereas those with a VA ≥ 6/12 were regarded as having no visual impairment. Linear regression was used to compare differences in mean VFQ-25, EQ-5D and TTO utility scores between groups, adjusted for age, sex and visual acuity. Results were considered to be statistically significant at the *P* < 0.05 level.

### Ethics approval

Written informed consent was obtained from all study participants. Ethics committee approval for this study was obtained from The University of Western Australia, Royal Perth Hospital, Sir Charles Gairdner Hospital and Fremantle Hospital and Health Service.

## RESULTS

Patient characteristics are summarized in Table 1. No significant differences existed between patient groups with regard to age, gender, Charlson Index of Comorbidity and Barthels Index of Activities of Daily Living. Whereas a comparable



**Table 1.** Comparison of patient characteristics between those who had postoperative endophthalmitis following cataract surgery (cases) and those who had uncomplicated cataract surgery (controls)

	Cases ( <i>n</i> = 19)	Controls ( <i>n</i> = 30)	<i>P</i> -value
Age (mean $\pm$ SD)	81.2 $\pm$ 8.5	76.60 $\pm$ 11.5	0.14*
Sex distribution			
Male	6 (32)	8 (27)	0.48**
Female	13 (68)	22 (73)	
Degree of vision loss			
No visual impairment	9 (47)	25 (83)	0.009**
Unilateral visual impairment	9 (47)	3 (10)	
Bilateral visual impairment	1 (6)	2 (7)	
General disability (mean $\pm$ SD)			
Charlson Index of Comorbidity Score	1.26 $\pm$ 1.2	1.20 $\pm$ 1.6	0.95*
Modified Barthels Index Score	103.7 $\pm$ 11.8	106.2 $\pm$ 7.4	0.25*

\*Two-tailed independent *t*-test. \*\*Fisher's exact test. Numbers in brackets are percentages.

**Table 2.** Comparison of postoperative visual acuity between patients who had postoperative endophthalmitis following cataract surgery (case) and those who had uncomplicated surgery (controls) in operated and non-operated eyes

Post-op VA	Operated eye		Non-operated eye	
	Cases	Controls	Cases	Controls
$\geq 6/6$	5	15	6	18
6/9	5	11	6	6
6/12	1	1	4	2
6/18	2	1	1	2
6/24	2	—	—	1
6/36	—	1	1	—
6/60	—	—	1	1
<6/60	4	1	—	—
<i>P</i> -value*	0.01		1	

\*Fisher's exact test comparing the proportion of eyes with postoperative distance visual acuity  $\geq 6/12$  and  $<6/12$  between cases and controls.

proportion of patients were vision impaired in either group, those who had postoperative endophthalmitis were more likely to have at least unilateral visual impairment (53% *vs.* 17%,  $P = 0.009$ ). Best-corrected distance VAs in operated and non-operated eyes in both groups are compared in Table 2. The proportion of postoperative endophthalmitis patients with VA  $< 6/12$  in their operated eye was significantly more than the comparison group ( $P = 0.01$ ).

Mean VFQ-25 subscale scores are summarized in Table 3. The age and sex-adjusted mean composite score, which combines all measured subscales included in the VFQ-25, was 13.5% lower for cases (95% confidence interval: 6–26.4,  $P < 0.01$ ). The mean scores for the general vision, near activities, mental health, role difficulties and peripheral vision subscales were all significantly lower in cases after adjusting for age, sex and visual acuity in the better eye. No significant differences were found for the other subscales.

Subgroup analysis comparing VFQ-25 subscale scores between groups with and without visual impairment

**Table 3.** Comparison of mean NEI VFQ-25 Subscale Scores in patients who had postoperative endophthalmitis (cases) following cataract surgery with those who did not (controls)

NEI VFQ-25 Subscale	Cases ( <i>n</i> = 19)	Controls ( <i>n</i> = 29)	<i>P</i> -value*
General health	55.0 $\pm$ 19.2	65.1 $\pm$ 23.3	0.13
General vision	64.2 $\pm$ 17.2	77.2 $\pm$ 20.0	0.01
Eye pain	79.6 $\pm$ 23.3	83.2 $\pm$ 22.0	0.44
Near activities	69.0 $\pm$ 32.5	85.8 $\pm$ 17.2	0.008
Distance activities	76.6 $\pm$ 26.2	86.0 $\pm$ 15.1	0.05
Social function	86.2 $\pm$ 27.0	93.0 $\pm$ 14.0	0.13
Mental health	69.7 $\pm$ 32.3	85.5 $\pm$ 22.3	0.02
Role difficulties	71.7 $\pm$ 32.3	87.3 $\pm$ 16.9	0.02
Driving <sup>†</sup>	64.6 $\pm$ 42.1	70.8 $\pm$ 32.1	0.91
Colour vision	90.8 $\pm$ 20.8	96.5 $\pm$ 14.5	0.17
Peripheral vision	69.4 $\pm$ 36.9	86.6 $\pm$ 22.0	0.02
Composite score	74.3 $\pm$ 22.7	85.9 $\pm$ 15.5	0.01

\*Adjusted for age, sex and visual acuity. <sup>†</sup>Controls (*n* = 16) and cases (*n* = 6). All values are given as mean  $\pm$  SD.

(VA  $< 6/12$  in at least one eye) showed that endophthalmitis cases without recorded visual impairment had lower scores in all but the driving subscale (Table 4). Similarly, among visually impaired participants, cases had consistently lower mean scores than controls in all subscales. None of these differences were found to be statistically significant for either group.

EQ-5D subscale scores are summarized in Table 5. Postoperative endophthalmitis patients reported poorer QOL in all domains of the EQ-5D compared with controls. The difference in summary score, which provides an overall average of each of the domains, though lower for endophthalmitis patients, was not significant. Only the difference found in the mobility domain (1.63 *vs.* 1.27) remained significant ( $P = 0.03$ ). Mean TTO utility values were slightly, but not significantly, lower for postoperative endophthalmitis patients (0.90 *vs.* 0.96,  $P = 0.12$ ).

**Table 4.** Mean NEI VFQ-25 Subscale Scores in patients who had postoperative endophthalmitis following cataract surgery (cases) with those who did not (controls) according to presence of visual impairment (visual acuity <6/12) in either eye

NEI VFQ-25 Subscale	No visual impairment		P-value*	Visual impairment		P-value*
	Cases (n = 9)	Controls (n = 24)		Cases (n = 10)	Controls (n = 5)	
General health	56.7 ± 18.9	62.6 ± 23.7	0.50	53.5 ± 20.3	77.0 ± 18.9	0.17
General vision	70.6 ± 19.1	79.0 ± 15.2	0.19	58.5 ± 20.0	69.0 ± 25.3	0.84
Eye pain	75.0 ± 27.2	80.2 ± 23.0	0.53	83.8 ± 19.6	97.5 ± 5.6	0.11
Near activities	78.8 ± 31.6	87.2 ± 14.4	0.20	60.2 ± 32.3	79.4 ± 28.6	0.46
Distance activities	80.1 ± 29.3	86.3 ± 14.9	0.32	73.4 ± 24.3	84.5 ± 17.8	0.69
Social function	87.0 ± 27.0	92.9 ± 14.1	0.29	85.4 ± 28.4	93.3 ± 14.9	0.81
Mental health	76.0 ± 33.3	88.1 ± 17.4	0.14	64.0 ± 31.9	73.0 ± 38.8	0.92
Role difficulties	79.2 ± 32.3	87.2 ± 16.4	0.27	65.0 ± 32.4	87.5 ± 21.2	0.49
Driving <sup>†</sup>	79.2 ± 36.1	68.6 ± 34.8	0.99	50.0 ± 50.0	80.6 ± 17.3	0.80
Colour vision	88.9 ± 25.3	99.0 ± 5.1	0.06	92.5 ± 16.9	85.0 ± 33.5	0.28
Peripheral vision	80.6 ± 32.5	88.5 ± 19.5	0.18	58.3 ± 39.5	75.0 ± 35.3	0.87
Composite score	79.2 ± 26.6	86.6 ± 14.3	0.21	69.8 ± 18.9	82.2 ± 22.2	0.64

\*Adjusted for age and sex. <sup>†</sup>No visual impairment: cases (n = 3) and controls (n = 13); visual impairment: cases (n = 3) and controls (n = 3). All values are given as mean ± SD.

**Table 5.** Mean EuroQOL EQ-5D Scores comparing patients who had postoperative endophthalmitis following cataract surgery (cases) with those who had uncomplicated surgery (controls)

EuroQOL EQ-5D Subscale	Cases (n = 19)	Controls (n = 30)	P-value*
Mobility	1.63 ± 0.50	1.27 ± 0.52	0.03
Self-care	1.16 ± 0.37	1.10 ± 0.48	0.63
Usual activities	1.47 ± 0.70	1.20 ± 0.55	0.16
Pain	1.79 ± 0.53	1.50 ± 0.63	0.12
Anxiety and depression	1.47 ± 0.49	1.33 ± 0.55	0.35
Summary score	0.66 ± 0.32	0.81 ± 0.25	0.08
General health state	68.4 ± 16.3	78.1 ± 16.7	0.07

\*Adjusted for age, sex and visual acuity. All values are given as mean ± SD.

## DISCUSSION

Our findings suggest that postoperative endophthalmitis following cataract surgery results in poorer patient perceived VRQOL compared with uncomplicated cataract surgery. Participants who had postoperative endophthalmitis were more likely to report difficulties in a range of vision-related activities involving near, distance, peripheral and general vision. They were also more dependent upon others, felt their vision limited the activities they could engage in and more likely to feel frustrated and worried because of their poor vision. However, no significant effect upon general health-related QOL was found.

Our findings of reduced VRQOL using the VFQ-25 were independent of VA in the better eye. This may have been because postoperative endophthalmitis patients were more likely to have unilateral vision loss, and although VRQOL is found to correlate most strongly with VA in the better eye, the presence of unilateral visual impairment is known to

cause poorer VRQOL.<sup>7,8,16</sup> When we restricted the comparison to those with no visual impairment in either eye and then compared mean VFQ-25 subscale scores, those with postoperative endophthalmitis still reported a lower QOL in all subscales except driving. Although these differences were not found to be significant in our study, it suggests that factors other than visual acuity may be affecting QOL in these patients.

Similar findings were reported in a study examining the effect of central retinal vein occlusion (CRVO) on QOL.<sup>17</sup> CRVO is similar to postoperative endophthalmitis in that it is an acute and predominantly unilateral complication resulting in sudden and severe vision loss. The VFQ-25 was used to measure VRQOL in 51 patients who had CRVO and who were compared with patients with normal vision and those with diabetic retinopathy. The authors found that patients with CRVO had significantly lower scores on several subscales in the VFQ-25 which also persisted after adjusting for VA of the better eye.

This contrasts previous studies that have found the impact of an eye disease on QOL is primarily dependent upon its effect on vision and independent of the underlying condition.<sup>18</sup> However, these studies involved chronic, slowly progressive eye diseases, unlike postoperative endophthalmitis, which tends to be an acute complication resulting in sudden and severe vision loss.<sup>3,19</sup> It also requires intensive and prolonged inpatient treatment, often with multiple procedures, and frequent and prolonged outpatient review. Patients are often independent and relatively healthy before developing postoperative endophthalmitis, and the impact of such a sudden and severe change in their perceived health, in addition to the sudden disruption to their life in order to treat it, is conceivably far greater than in a chronically progressive eye condition that allows greater time for the patient to adapt.

We found mean TTO utility and EQ-5D scores were generally worse among cases and suggests postoperative endophthalmitis has some impact on self-perceived general health-related QOL. However, these differences did not reach statistical significance in our study, despite approaching it on several subscales. This is likely due to a combination of our small sample size and the relative insensitivity of the EQ-5D and TTO for detecting more subtle vision-related impacts on QOL detected by the VFQ-25.<sup>20,21</sup> Espallargues *et al.*, in their study of 209 patients with substantial vision loss due to age-related macular degeneration, found that the EQ-5D did not reflect the reductions in health status in terms of visual impairment and function detected by more specific vision related measures. They argued that the lack of sensitivity of the EQ-5D relates to the relevance of its descriptive systems, which fail to capture the impact of daily living activities that rely upon central vision.<sup>21</sup>

We identified several potential limitations to this study. The sample size is relatively small, because of the rarity of postoperative endophthalmitis in the community, and limited our ability to assess more subtle changes in QOL between groups. Reporting bias exists owing to differences in questionnaire delivery to cases and controls as interviewer bias may have been introduced for cases that was not present among controls (who were given self-administered questionnaires). Furthermore, it was also not possible to know whether the questionnaire was truly self-administered to controls or whether a family member or carer aided in its administration. Previous studies show that proxy respondents tend to over-report problems compared with patients.<sup>22</sup> Should this have occurred in our study, it would have resulted in a smaller difference between cases and controls and lead to an underestimation of true QOL scores.

Our study is strengthened by its population-based design and its use of widely accepted QOL measurement tools. The VFQ-25 questionnaire is a scientifically validated, widely used and easily administered tool for evaluating self-reported VRQOL in patients with visual impairment from a range of ages and cultural backgrounds.<sup>23–25</sup> It has been used successfully to assess the impact of numerous acute and chronic eye conditions on QOL including diabetic retinopathy,<sup>26</sup> age-related macular degeneration<sup>27</sup> and glaucoma.<sup>28</sup> The EQ-5D is used widely in general health-related QOL research, where its validity is well established;<sup>12</sup> however, its utility as a measure of the impact of vision on health-related QOL is variable.<sup>21,29</sup> Utility analysis is also regarded as a valid measure of VRQOL<sup>30</sup> and is becoming increasingly important in the study of values-based outcomes in ophthalmology.<sup>31</sup> Studies have shown that TTO utility correlates most strongly with the VA of the better seeing eye.<sup>32</sup>

Postoperative endophthalmitis remains a severe and potentially devastating complication of cataract surgery. We found that postoperative endophthalmitis has a measureable impact upon the psychological well-being of patients and their ability to maintain a normal role in daily life beyond its affect on VA. The measurement of patient perceived QOL as

an additional outcome measure to VA (using reliable and easily administered questionnaires such the VFQ-25) is a useful tool for clinicians to provide a more complete understanding of the impact of postoperative endophthalmitis and treatment outcomes on QOL than can be gleaned from VA alone.

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## Original Article

## Quality of life of the most severely vision-impaired

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**ABSTRACT**

**Background:** To explore the interaction between vision impairment, perceived quality of life loss and willingness to trade remaining life for vision gain.

**Design:** Community-based cross-sectional study

**Participants:** Legally blind or severely vision-impaired people selected randomly from the Association for the Blind of Western Australia register.

**Methods:** Individuals were examined by consultant ophthalmologists and completed the Impact of Vision Impairment profile quality of life assessment and a Time Trade-Off evaluation. Vision-related utility values were calculated. The results were analysed using univariate and multivariate regression methods.

**Main Outcome Measures:** IVI Rasch Logits and TTO utility values (TTO UV).

**Results:** 156 people volunteered to contribute to the study. The median age was 80 (19–97) years, and 56% were female. Being legally blind (logMAR > 1) (95% CI 1.1 to 5.2,  $P = 0.003$ ), clinically depressed (95% CI -11.2 to -1.8,  $P = 0.007$ ) or more than 40 years of age (95% CI 0.9 to 8.1,  $P = 0.015$ ) significantly lowered overall impact of vision impairment scores. The emotional domain of impact of vision impairment was associated with willingness to trade part of remaining life. A 5-Logit increase in impact of vision impairment emotional score resulted in a 21% (95% CI 10 to 31) decrease in the

odds of being likely to trade life for sight. The Australian definition of blindness compared with World Health Organisation or USA best separates those with perceived loss and appears useful in identifying vision loss-related morbidity.

**Conclusions:** These results suggest that emotional health and lack of depression are important determinants for quality and value of life.

**Key words:** blind, depression, IVI assessment, quality of life, time trade-off utility value.

**INTRODUCTION**

A blinding eye condition can be a devastating disability, leading to depression,<sup>1,2</sup> loss of employment, financial stress<sup>3</sup> and premature death.<sup>4</sup> The total cost of vision-related disorders in Australia has been estimated to be \$9.85 billion per annum.<sup>5,6</sup> We wanted to explore how visual function, varying diagnoses and length of onset of severe vision impairment and blindness affected quality of life. And in particular, what was the interaction between the subjective impact of vision impairment (IVI) and time trade-off utility values (TTO UVs)?

The IVI questionnaire is a well-validated tool developed in Australia to evaluate self-reported performance of tasks associated with everyday living. It has three component domains of mobility, reading or recognition tasks and emotional well-being, which together combine to give an overall IVI score.<sup>7</sup>

Time trade-off utility values are used by health economists to quantify and compare patient

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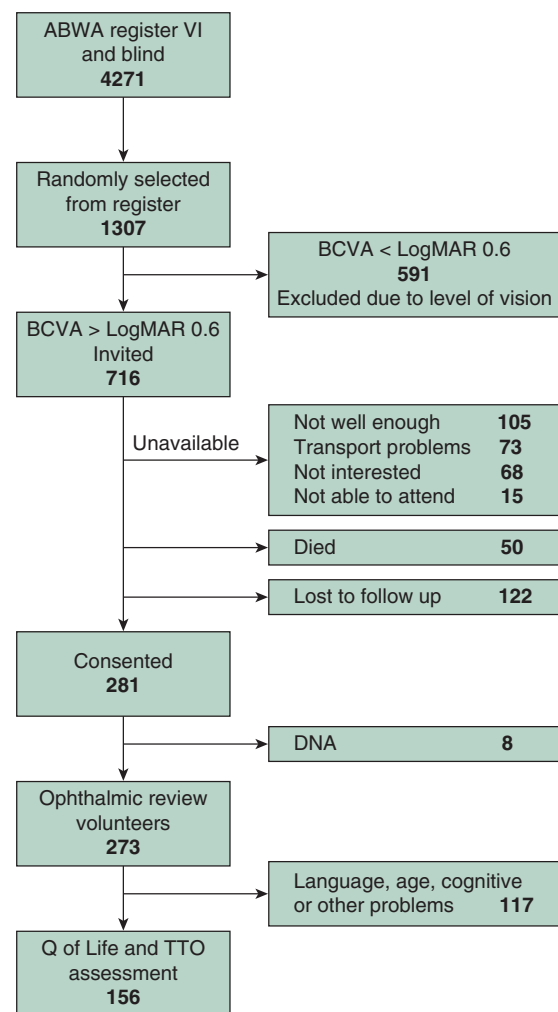
preferences across a range of diseases and health states.<sup>8</sup> By using TTO UV to evaluate and objectively assess quality of life, economists can perform a cost-utility analysis. The UV multiplied by the remaining years of life gives the 'quality-adjusted' life years (QALYs); an effective intervention that costs less than about \$50 000 per QALY is considered reasonable value for money.<sup>9</sup>

## METHODS

The Association for the Blind of Western Australia maintains a register of vision-impaired and legally blind members ( $n = 4271$ ). Individuals were randomly selected from the register and then subselected if they were severely vision-impaired or 'near blind' (Fig. 1). For the purposes of this study this 'near blind' was defined as having a previous Association for the Blind of Western Australia clinical record, as determined by an ophthalmologist or optometrist, of a best-corrected visual acuity (BCVA) of  $\log\text{MAR} > 0.6$  or  $< 20^\circ$  diameter of field, or a combination of both reduced VA and field restriction, in the better eye. Legal blindness in Australia is confirmed when the better eye has a VA  $\log\text{MAR} > 1$  or field of  $< 10^\circ$  diameter, or a combination of both visual acuity and field loss that results in the equivalent level of vision loss. Study volunteers were aged at least 18 years and able to travel to attend the clinical appraisal. Consent was obtained from all participants after the study aims and purpose were explained. The research project was approved by the Human Research Ethics Committee of Curtin University.

Each individual was clinically reviewed by one of two consultant ophthalmologists (WM, NM) to determine the cause of vision loss and establish the current level of vision loss. Best-corrected distance VA for each eye was measured using a logMAR chart, at 6 and 3 m, in standardized lighting conditions. In this study counting fingers, hand movements, perception of light and no perception of light were assigned logMAR values of 2, 3, 3.5 and 4, respectively. Field restriction was mapped using a Bjerrum screen, with a 10-mm target at 1 m distance, for each eye. Existing comorbidities were obtained by self-report during this assessment. Any history of cognitive or neurological impairment that was reported by individuals or carers, or individuals who were unable to understand the questions were excluded from the study.

A standardized verbal interview was carried out by a single interviewer (JC), to collect demographic details. All data were entered and stored in a database created in Microsoft Access (v 2007). We employed two validated tools to measure the effects of vision loss; the IVI questionnaire<sup>10</sup> and a TTO



**Figure 1.** Flow diagram to describe the cohort selection process. A total of 1307 vision-impaired people were randomly selected from the register. Individuals who were 'near blind' ( $n = 716$ ) were invited to be part of the study and 281 agreed to attend the clinics. Of these, 156 volunteered to complete the impact of vision impairment and time trade-off assessments. ABWA, Association for the Blind of Western Australia; BCVA, best-corrected visual acuity; TTO, time trade-off utility; VI, vision-impaired.

question.<sup>11–13</sup> Participants unable or unwilling to complete both IVI and TTO assessments were excluded from the analysis.

Responses to the IVI questionnaire were selected from a list of choices, by the patient, as either 'not at all' (3), 'a little' (2), 'a fair amount' (1) to 'a lot' (0). There was provision for 'don't do this for reasons other than vision loss' (8). Overall IVI score and mean IVI score were calculated for each domain: mobility, emotional effects and reading/recognition skills. Items rated 8 were excluded from the calculation. A score conversion based on Rasch

analysis was performed as described by others.<sup>7,14</sup> Student's *t*-tests and standard linear regression models, to account for multiple predictors, were used to estimate the effect of demographic and clinical factors on the overall IVI scores and for each of the three domain scores. The most parsimonious models were constructed whereby factors not significantly associated with the dependent variable were removed.

A TTO question quantifies a person's preference for a preferred health status. In this study, the scores ranged between 0 (total blindness) and 1 (perfect vision) and represent a measure of global or illness-specific quality of life.<sup>15</sup> UVs have been used to objectively assess quality of life associated with health states across different medical specialities.<sup>8</sup> In the TTO assessment, participants were asked to quantify how much, if any, of their own estimate of remaining life they would be prepared to trade if their sight could be restored, as described and validated by others.<sup>11–13</sup> This estimate was converted to a percentage of their remaining years of life. A TTO UV was then calculated:

$$\text{UV} = 1 - (\text{years to trade-off} / \text{years of remaining life})$$

Demographic and clinical factors associated with variations in the TTO UV were investigated using Tobit regression models to account for the bounded nature of the dependent variable on the (0, 1) interval showing a truncated normal distribution.

Stata v10 (Stata Corporation, College Station, TX, USA) and SPSS v17 (SPSS Inc., Chicago, IL, USA) were used for all analyses.

## RESULTS

One thousand three hundred and seven individuals were randomly selected from the register of blind and vision impaired in Western Australia. Of these, 716 were considered to be 'near blind' and eligible for inclusion in this study. There were 122 who had no known contact details and 50 who had died since last contacted. A further 263 (48%) declined to join the study being either not well enough, having transport difficulties, not interested or were unable to attend. One hundred and fifty-six individuals volunteered for a full ophthalmic review and to complete the IVI and TTO assessments (Fig. 1). The demographic details of this cohort are shown in Table 1. There were more female ( $n = 86$ ) than male ( $n = 70$ ), and the age of the cohort ranged from 19 to 97 years (mean 74 years, median 80 years). 'Legal blindness' was found in 82% ( $n = 128$ ); the remaining 18% ( $n = 28$ ) were termed 'near blind' for the purposes of this study, having a BCVA of logMAR 0.6–1 with or without field restriction. Age-related macular degeneration was the primary cause of

vision loss in 60% ( $n = 94$ ) of the participants; of these, 62% were neovascular and 38% atrophic. The remaining causes were: congenital retinal dystrophies 15.4% ( $n = 24$ ), optic neuropathies 5.4% ( $n = 8$ ), diabetic retinopathy 4.5% ( $n = 7$ ), glaucoma 3.2% ( $n = 5$ ), myopia 2% ( $n = 3$ ), vein occlusions 1.3% ( $n = 2$ ), cataract 0.6% ( $n = 1$ ) and other 7.6% ( $n = 12$ ). Only 8% ( $n = 13$ ) of participants were diagnosed with a blinding eye condition in childhood (aged less than 12 years). More than half had become legally blind within the last 10 years, range 1–70 years (mean 11 years, median 8 years).

Comorbidities were self-reported by 80% ( $n = 124$ ) of individuals, and 46% ( $n = 71$ ) had two or more comorbid conditions. Almost half the individuals with comorbidities had hypertension 42%, ischaemic heart conditions 17%, diabetes 18%, cerebrovascular disease 5%, cancer/neoplasm 5% and depression 3%.

## Factors associated with IVI score outcomes

Univariate analysis indicated that being legally blind in Australia: having a BCVA logMAR  $> 1$  or field loss of  $10^\circ$  or a combination of reduced VA and field loss was associated with a 6-Logit lower mean overall IVI score (Table 1) compared with IVI scores for people who were near blind (BCVA logMAR 0.6–1). This difference remained highly significant (3.1, 95% CI 1.1 to 5.2,  $P = 0.003$ ) after adjustment for other factors using multivariate modelling (Table 2). We also analysed the alternate cut-off points that the World Health Organisation (WHO) (BCVA logMAR  $> 1.3$ ) and USA (BCVA logMAR  $\geq 1$ ) used to define blindness. The mean difference in overall IVI scores between near blind and blind was greatest (6 Logits) using the Australian definition of legal blindness compared with the WHO (4 Logits) or US definitions (2 Logits). There was no significant difference in the mean IVI scores between individuals who had a BCVA logMAR  $\leq 1$ , with ( $n = 24$ ) or without ( $n = 28$ ) field restriction, nor between legally blind people who had BCVA logMAR  $< 1$  but with limited fields ( $n = 24$ ) and all other legally blind people BCVA logMAR  $> 1$  ( $n = 104$ ) (data not shown).

In this study, being 'legally blind' rather than 'near blind' was associated with a significantly lower mean overall IVI score (3.1, 95% CI 1.1 to 5.2,  $P = 0.003$ ).

Across the IVI domain categories, the single factor that was most consistently associated with significantly lower IVI scores was the presence of depression as a comorbidity ( $n = 6$ ). Although this is a small number in a cohort of 156, the association remained significant in regression analysis. In patients with a self-reported diagnosis of depression



**Table 1.** Univariate analysis of Rasch adjusted IVI scores and TTO UVs for demographic and vision characteristics, using independent *t*-test

	<i>n</i>	Mean IVI			
		Overall score $\pm$ SD	Emotion score $\pm$ SD	Reading score $\pm$ SD	Mobility score $\pm$ SD
Total	156	51 $\pm$ 12.2	59 $\pm$ 15.5	52 $\pm$ 10.9	55 $\pm$ 10.7
Gender					
Male	70	52 $\pm$ 11.7	58 $\pm$ 15.1	52 $\pm$ 11.5	57 $\pm$ 10.3
Female	86	50 $\pm$ 12.6	59 $\pm$ 15.8	51 $\pm$ 11.5	54 $\pm$ 10.8
Vision					
Australian near blind	28	57 $\pm$ 12.3*	62 $\pm$ 13.9	58 $\pm$ 10.9*	59 $\pm$ 12.3*
Australian legal blind	128	51 $\pm$ 11.9*	59 $\pm$ 15.8	50 $\pm$ 10.5*	54 $\pm$ 10.1*
logMAR > 1+ field loss					
USA near blind	33	57 $\pm$ 11.5	59 $\pm$ 16.2	58 $\pm$ 12.2 <sup>†</sup>	56 $\pm$ 11.5
USA legal blind	123	55 $\pm$ 9.7	59 $\pm$ 15.4	50 $\pm$ 9.9 <sup>†</sup>	55 $\pm$ 10.5
logMAR $\geq$ 1					
WHO near blind	99	57 $\pm$ 10.1	60 $\pm$ 15.1	54 $\pm$ 11.1 <sup>‡</sup>	56 $\pm$ 10.7
WHO legal blind	57	53 $\pm$ 9.8	58 $\pm$ 16.2	47 $\pm$ 8.9 <sup>‡</sup>	54 $\pm$ 10.5
logMAR > 1.3					
Median age = 80					
<80 years	76	51 $\pm$ 12.8	57 $\pm$ 16.7	53 $\pm$ 11.5	54 $\pm$ 10.6
$\geq$ 79 years	80	52 $\pm$ 11.6	61 $\pm$ 14.0	51 $\pm$ 10.3	56 $\pm$ 10.7
Comorbidities					
No	31	55 $\pm$ 13.6	60 $\pm$ 15.3	57 $\pm$ 13.1	57 $\pm$ 11.2
Yes	125	51 $\pm$ 11.7	59 $\pm$ 15.6	51 $\pm$ 10.4	55 $\pm$ 10.5
Age of onset					
<12 years	13	55 $\pm$ 10.4	65 $\pm$ 12.5	55 $\pm$ 10.2	55 $\pm$ 9.4
$\geq$ 12 years	143	51 $\pm$ 12.3	59 $\pm$ 15.7	52 $\pm$ 10.9	55 $\pm$ 10.8
Education					
Primary only	9	44 $\pm$ 10.3	54 $\pm$ 11.1	45 $\pm$ 14.0	46 $\pm$ 8.9*
Secondary	121	51 $\pm$ 12.2	59 $\pm$ 16.3	51 $\pm$ 9.4**	56 $\pm$ 10.6*
Tertiary	25	55 $\pm$ 11.9	59 $\pm$ 12.5	58 $\pm$ 14.4**	57 $\pm$ 10.8
Unknown	1				
TTO UV					
Traders	107	53 $\pm$ 9.1*	56 $\pm$ 13.9 <sup>†</sup>	50 $\pm$ 10.0 <sup>‡</sup>	54 $\pm$ 9.4**
Non-traders	49	60 $\pm$ 11.1*	65 $\pm$ 16.9 <sup>†</sup>	54 $\pm$ 12.4 <sup>‡</sup>	59 $\pm$ 12.2**

\*, \*\*, †, ‡ indicate where significant differences were found between separate data sets  $P < 0.05$ . IVI, impact of vision impairment; SD, standard deviation; TTO UV, time trade-off utility value.

overall mean IVI score was 6.5 Logits worse (95% CI  $-11.2$  to  $-1.8$ ,  $P = 0.007$ ), mean mobility IVI scores were 11.5 Logits worse (95% CI  $-20.5$  to  $-2.4$ ,  $P = 0.013$ ), and emotion IVI scores were 17 Logits worse (95% CI  $-30$  to  $-3.8$ ,  $P = 0.012$ ) compared with those of people without a diagnosis of depression (Table 2).

The only other comorbidity that was shown to impact on overall mean IVI score was any form of cancer/neoplasm ( $n = 8$ ). This was associated with better overall IVI scores, mean 4.5 Logits (95% CI 1.0 to 8.1,  $P = 0.013$ ).

Patients aged less than 40 years had significantly better mean overall IVI scores (4.5, 95% CI 0.9 to 8.1,  $P = 0.015$ ) and IVI reading/recognition domain scores compared with those aged more than 40 years (12.6, 95% CI 5.2 to  $-20.0$ ,  $P = 0.001$ ). Regression analysis demonstrated that better IVI reading/recognition scores were associated with a higher level of education completed (5.3, 95% CI 0.9 to 9.7,  $P = 0.02$ ).

The completion of a secondary education compared with primary only education was significantly associated with a higher mean IVI mobility score in the adjusted regression model ( $-8.1$ , 95% CI  $-14.9$  to  $-1.3$ ,  $P = 0.019$ ) (Table 2).

### Factors associated with TTO UVs

There were no significant differences in the demographics or health-related factors (age, gender, age of onset, years since onset, level of vision loss) of those who would ( $n = 107$ ) or would not trade ( $n = 49$ ) some years of remaining life for sight restoration. Nor was there any significant difference in TTO UV of those people who were legally blind (logMAR > 1) ( $n = 128$ ) and those who were 'near blind' (logMAR  $\leq$  1) ( $n = 28$ ).

Because of the bounded nature (0, 1) of the TTO UVs, a single Tobit regression model found that age group was the only demographic variable that was

**Table 2.** Demographic and clinical factors associated with mean IVI scores as estimated by four separate linear regression models for total IVI scores and the emotion, reading and mobility domains ( $n = 156$ )

	Difference in mean IVI scores <sup>†</sup>	95% CI	P-value
Total IVI			
Age group (years)			
<40	4.5	0.9–8.1	0.015
40–59	–0.2	–3.1–2.7	0.896
60–79	–0.7	–2.4–1.1	0.436
80+	Referent group		
logMAR $\leq 1$	3.1	1.1–5.2	0.003
Depression	–6.5	–11.2–1.8	0.007
Neoplasms	4.5	1.0–8.1	0.013
Traders	–2.8	–4.5–1.1	0.001
Emotion IVI			
Depression	–16.9	–30–3.8	0.012
Traders	–9.2	–14.1–4.2	0.001
Reading IVI			
Age group (years)			
<40	12.6	5.2–20.0	0.001
40–59	3.4	–2.2–9.0	0.227
60–79	1.2	–2.3–4.7	0.489
80+	Referent group		
Education			
Primary	–5.4	–12.1–1.2	0.109
Secondary	Referent group		
Tertiary	5.3	0.9–9.7	0.020
logMAR $\leq 1$	7.1	3.0–11.2	0.001
Neoplasms	–6.5	–11.7–1.3	0.014
Traders	–3.7	–7.1–0.3	0.032
Mobility IVI			
Education			
Primary	–8.1	–14.9–1.3	0.019
Secondary	Referent group		
Tertiary	1.9	–2.4–6.3	0.379
logMAR $\leq 1$	4.5	0.4–8.7	0.031
Depression	–11.5	–20.5–2.4	0.013
Traders	–5.6	–9.0–2.2	0.001

Only variables showing a statistically significant association were included in each of the final models. <sup>†</sup>Difference in mean score between those with the variable of interest compared with those without the variable of interest (or the referent group where appropriate). CI, confidence interval; IVI, impact of vision impairment.

**Table 3.** Demographic, clinical and IVI factors associated with Time Trade-Off utility value scores as estimated from a single Tobit regression model that accounts for the bounded nature (0, 1) of the TTO utility values

Variable	Difference in mean IVI scores*	95% CI	P-value
Age group (years)			
<40	0.31	0.03–0.58	0.030
40–59	0.11	–0.07–0.30	0.219
60–79	0.04	–0.08–0.16	0.499
80+	Referent group		
Emotion IVI scores (5 Logits)	0.04	0.02–0.06	<0.001

Only variables that were statistically significant at an alpha level of 0.05 are included in the final model.

associated with the TTO UV. Participants aged less than 40 years ( $n = 8$ ) had significantly higher mean TTO UVs (95% CI 0.03 to 0.58,  $P = 0.03$ ) compared with older participants (Table 3).

No comorbidities, such as: diabetes, depression, vascular disease, hypertension, arthritis or joint

problems, any form of neoplasia or the total number of comorbidities had any significant effect TTO UV scores in this cohort.

Although vision-specific tools for quantifying health status UVs are not truly comparable across diverse medical states,<sup>16</sup> others have made this

**Table 4.** Comparison of mean IVI scores for near blind and legally blind who would (traders) and would not trade (zero traders) some years of remaining life for sight restoration

	<i>n</i>	Near blind, mean $\pm$ SD	<i>n</i>	Legally blind, mean $\pm$ SD	<i>P</i> -value
Total IVI score					
Zero traders	8	68 $\pm$ 9.8	41	58 $\pm$ 10.7	0.02*
Traders	20	56 $\pm$ 8.1	87	53 $\pm$ 9.2	0.11
<i>P</i> -value		0.003*		0.004*	
IVI emotion score					
Zero traders	8	70 $\pm$ 10.7	41	64 $\pm$ 17.9	0.38
Traders	20	58 $\pm$ 13.7	87	56 $\pm$ 14	0.46
<i>P</i> -value		0.032*		0.002*	
IVI reading score					
Zero traders	8	64 $\pm$ 15.9	41	52 $\pm$ 10.7	0.01*
Traders	20	55 $\pm$ 7.1	87	49 $\pm$ 10.3	0.006*
<i>P</i> -value		0.039*		0.13	
IVI mobility score					
Zero traders	8	69 $\pm$ 12.7	41	57 $\pm$ 11.2	0.01*
Traders	20	55 $\pm$ 9.9	87	53 $\pm$ 9.3	0.43
<i>P</i> -value		0.004*		0.033*	

\*indicates where significant differences were found for  $P < 0.05$  using independent *t* test. *n* is the number in each category. IVI, impact of vision impairment; SD, standard deviation.

comparison.<sup>15,17,18</sup> Severe vision loss was rated comparable with colon cancer (UV 0.8), a diagnosis of AIDS (0.79), moderate stroke (UV 0.73) or having a failed kidney transplant (UV 0.62) (Table 5).<sup>15</sup>

### Combined TTO UV and IVI scores outcomes

We found that 49 individuals would not consider trading any years of remaining life for their sight restoration (TTO UV = 1). The majority (84%) of these 'zero traders' were also legally blind ( $n = 41$ ). Using an independent *t*-test, zero traders had mean overall IVI Logit score of 60 compared with 'traders' (people who were prepared to trade some life for sight restoration [TTO UV < 1]) who had a mean overall IVI Logit score of 54 (mean difference = 6.4, 95% CI 3.0 to 9.7,  $P = 0.000$ ). Zero traders also had significantly higher scores in the three IVI subdomains, except for the IVI reading domain in legally blind individuals (Table 4).

There was a strong association between an individual's TTO UV and IVI emotion domain score, where every 5-Logit increase in the domain score increased the TTO UV 4%. However there were no other demographic or clinical variables associated with differences in the TTO UVs.

Similarly, when the TTO UV was used to categorize participants as either traders or zero traders, we found that the odds of being a trader was significantly associated with the IVI emotion domain score. Every 5-Logit increase in the IVI emotion domain score was associated with a 21% (95% CI 10 to 31) decrease in the odds of being a trader. Again no other

demographic or clinical factors were associated with the odds of being a trader or not.

No specific diagnostic cause of vision loss was associated with any difference in any of the TTO UV or IVI scores in the multivariate analysis.

### DISCUSSION

We found that the cut-off level for legal blindness in Australia (logMAR > 1) coincided with significant differences in mean IVI scores when compared with other visual acuity cut-off points used by WHO and in other countries. However, in this cohort we did not find that field restriction made a significant difference to IVI scores compared with equally vision-impaired subgroups with no field loss or more severely blind subgroups. This is consistent with findings of other research groups who found that reduced visual acuity rather than visual field loss was a stronger determinant for reduced daily living activities.<sup>19</sup> In this cohort, people found to be legally blind at review had significantly worse overall IVI, mobility and reading/recognition skill scores when compared with individuals found to be near blind.

The most marked finding in this group was that people who self-reported a diagnosis of a depressive illness had significantly lower IVI scores across all domains. Despite the small numbers, the statistical effect remained significant after controlling for other factors and had the strongest impact on the IVI emotion component. This finding is consistent with that of others who have reported a strong association between vision impairment and depressive symptoms.<sup>20–22</sup> These groups reported depression affect-

**Table 5.** Comparisons of reported utility value scores for cohorts with similar levels of vision loss

Authors	Reference	<i>n</i>	logMAR VA	TTO UV	SD	95% CI
Brown <i>et al.</i>	8	33	1–1.3	0.65	0.08	0.58–0.72
		17	2–3	0.47	0.29	0.33–0.61
Shah <i>et al.</i>	28	22	>0.9	0.76	0.23	0.73–0.87
Aspinall <i>et al.</i>	29	n/a	1–1.3	0.68	n/a	0.38–0.66
		n/a	1.4–5	0.76	n/a	0.29–0.50
Knauer and Pfeiffer	15	n/a	>0.9	0.61	0.19	0.57–0.65
This study		52	0.6–1	0.78	0.23	0.72–0.85
		47	1.1–1.3	0.75	0.26	0.67–0.83
		27	1.4–1.9	0.67	0.26	0.56–0.77
		30	2–4	0.72	0.27	0.61–0.82
		107	Traders only	0.62	0.22	0.58–0.67

CI, confidence interval; n/a, not available; SD, standard deviation; TTO UV, time trade-off utility value; VA, visual acuity.

ing larger percentages of the vision-impaired than found in the present study, which may be because we did not specifically assess for depression, relying instead on self-reporting. It is possible that people with depression may be less likely to volunteer to attend a study clinic, so were underrepresented in the present study. Depression compounds the disability resulting from vision loss, reducing quality of life, physical and mental functioning, as well as increasing disability.<sup>1,2</sup> However depression is treatable, leading to dramatic improvements in functional status, disability and quality of life.<sup>23</sup>

Most people (80%) in this cohort of blind or near blind individuals had some form of comorbidity, which is similar to that found by others.<sup>24,25</sup> Adverse outcomes associated with both vision impairment and comorbidities have been reported by several groups.<sup>2,26</sup> Brody *et al.*<sup>2</sup> reported that the level of vision loss alone is not an indicator for the onset of depression, but where vision loss was combined with any comorbidity, there was a significant risk of depression.

Those who attended the assessment clinics were necessarily relatively healthy, mobile and had carer support, so we may have underestimated the extent of disability and depression associated with severe vision loss. Also we relied on self-reporting of medical comorbidities and did not assess their severity. Despite these limitations, our findings were consistent with previous research, indicating that vision loss and depression are associated with declines in a range of health indicators.

Interestingly, a diagnosis of cancer or neoplasia was found to be associated with better overall mean IVI scores. Others have not reported this effect, to the best of our knowledge, and the small numbers affected in this cohort suggest that the results should be tested in a study suitably powered to detect a difference. It may indicate a personal re-evaluation of the impact of vision loss in the context of a life-threatening condition.

Despite the cohort's median age (80 years), we found that the participants had little or no problem with the concept of the TTO methodology, contrary to reports by others.<sup>27</sup> The number that would consider trading some life for restoration of their sight (68%) was similar to other studies (Table 5).<sup>8,15,28,29</sup> The IVI emotion scores and being aged less than 40 years were the only variables that had significantly higher TTO UV scores in a regression analysis (Table 3). There was no significant difference in TTO UV scores with any other demographic or clinical factors tested in this cohort (diagnostic cause or level of vision loss, education level, rural or urban residency or the presence of comorbidities). Overall we found that those who were legally blind did not have significantly worse TTO UV scores than people who were 'near blind'. However we did find that those who were not prepared to trade any years of remaining life for sight (zero traders) did have significantly better IVI scores than the group who were willing to trade life for sight. In particular, higher IVI emotion scores were associated with zero traders, implying that they were coping better with everyday living and its associated tasks, and that future life had value.

Blinding eye disease is a serious public health problem endangering personal confidence and independence, autonomy and quality of life. We found that older people with severe levels of vision loss were most adversely affected by their disability, especially when depressed. However, we also found that those with good coping skills were less inclined to trade life for sight in TTO assessments, strongly implying that emotional health and lack of depression are important determinants of quality and value of life. Whether this relates to successful rehabilitation requires further study.

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#### **4.4. Published letters**



# Ting DS, Morlet N, Clark A, Ng JQ, Yuen J and Preen DB. Differences in diabetic retinopathy management by primary eye care providers in Australia. *Clinical & Experimental Ophthalmology* 2011; 39(6): 585–586.

nizations and WHO were listed as other potential sources of financial and technical support.

Although limited in scope, this survey indicates that eye health promotion is not included in general health promotion programmes, nor systematically within eye programmes in WPIC. Despite this, the majority of participants indicated interest in, and acknowledged benefits of including eye health promotion within the services they deliver. Further, they perceived their Health Promotion Departments would support their eye health promotion efforts. It is likely that context-specific solutions need to be found to address this apparent disconnect. Collaboration between eye care personnel, other active agencies and WPIC Health Promotion Departments may result in the inclusion of eye health in general health promotion initiatives, as well as support for specific eye health initiatives. If such collaborations enable eye care personnel to be more active, and to employ approaches to health promotion that are more participatory and creative (e.g. integration into outreach activities, collaboration with community groups and the use of radio, photo-novellas or drama), they may contribute to more comprehensive eye programmes, preventing problems and promoting eye health.

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Jacqueline Ramke MPH and  
R       du Toit MPH**  
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Auckland, New Zealand  
Received 11 November 2010; accepted 12 December 2010.

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## Differences in diabetic retinopathy management by primary eye care providers in Australia

The number of people with diabetes mellitus across the globe is expected to double by 2030.<sup>1</sup> According to AusDiab Study in 2003, the prevalence of diabetic retinopathy (DR) in Australia was 22% in people with type 2 diabetes and 6.2% in those newly diagnosed.<sup>2</sup>

The National Health and Medical Research Council recently updated their evidence-based DR clinical practice guidelines, encouraging the primary eye care providers such as the general practitioners (GPs) and optometrists to play a role in community screening for DR.

During 2007 and 2008, we sent out 3000 self-administered questionnaires enquiring about routine DR management practices to a random sample of GPs and optometrists across all States in Australia.<sup>3,4</sup> A total of 429 GPs (21%,  $n = 429/2000$ ) and 569 optometrists (57%,  $n = 569/1000$ ) responded. Both rural (33%) and metropolitan practitioners (67%) were represented in the survey sample. The results reporting screening barriers and management with referral are shown in Table 1.

We found nearly 80% of optometrists reported having a strong desire to screen for DR and only 40% of GPs. Practical barriers and poor diagnostic confidence may be the main reason for the lack of enthusiasm among GPs.

Funduscopy using the direct ophthalmoscope is an essential basic medical examination skill. In the absence of retinal photography or a slit lamp, ophthalmoscopy with dilation is still the optimal method to examine for signs of DR in the primary eye care setting.

A fear of causing acute angle closure glaucoma with dilating drops is still a concern despite the exceedingly low risk (1 in 20 000).<sup>5</sup> Even in the rare event that an acute angle closure glaucoma attack is precipitated, it is readily treatable and provides the patient with a diagnosis in a supportive setting. Therefore, such a fear should not be seen as a barrier.

It is concerning that nearly 60% of optometrists would not refer patients with diabetic macular oedema (Table 1).<sup>3</sup> This warrants a call for action, as diabetic maculopathy causes most of the significant visual impairment from diabetes. Although macular oedema may be difficult to detect with direct ophthalmoscopy or colour fundus photography, any unexplained drop in visual acuity always should be suspicious and prompt an early referral to an ophthalmologist.

**Table 1.** Management differences between GPs and optometrists who responded to an Australian National Survey (2008–2009)

Screening barriers	GPs	Optometrists	P-value
(1) Lack of confidence in detecting changes using dilated funduscopy	86%	2%	<0.001
(2) Time limitations	73%	13%	<0.001
(3) Patients unpreparedness to drive	64%	51%	<0.001
(4) Fear of angle closure glaucoma	44%	13%	<0.001
Referral of findings to ophthalmologists			
(1) Severe non-proliferative DR	99%	90%	<0.001
(2) Proliferative DR	99%	98%	<0.05
(3) Macular oedema	86%	40%	<0.001

The significance of differences was determined by Pearson  $\chi^2$ -test. DR, diabetic retinopathy; GP, general practitioner.

**Daniel SW Ting MBBS(Hons),<sup>1,2</sup> Nigel Morlet FRANZCO,<sup>3</sup> Antony Clark MBBS(Hons),<sup>1</sup> Jonathon Q Ng MBBS PhD,<sup>1</sup> Joshua Yuen MBBS MPH<sup>1</sup> and David B Preen PhD<sup>1</sup>**  
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Received 16 November 2010; accepted 18 November 2010.

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# Clark A, Morgan WH, Kain S, Farah H, Armstrong K, Preen DB, Semmens JB, Yu DY. Diabetic Retinopathy in Australian Aboriginal people: response. *Clinical and Experimental Ophthalmology* 2011; 39 (2): 185-186.

## Clinical & Experimental Ophthalmology

Letters to the Editor

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Received 6 September 2010; accepted 7 September 2010.

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### Diabetic retinopathy in Australian Aboriginal people

It is with much interest that I read the paper by Antony Clark and co-workers that reports the findings of multiple visits to the Eastern Goldfields in Western Australia and documents their findings over a 12-year period.<sup>1</sup> This work is highly commendable although of course it does miss many of the Aboriginal communities in the north-eastern part of their area. Overall, they examined some 920 people over the age of 16 out of a population in excess of 4000 in that age range. Nevertheless, their findings are useful and important.

One area that does need correction is the very clear statement by the National Health and Medical Research Council Guidelines on diabetic retinopathy that Aboriginal and Torres Strait Islander people with diabetes need to have their eyes examined on an annual basis.<sup>2,3</sup> In their paper, Clark and co-workers misquote this as recommendation to be seen within 2 years. The biennial examination is the recommendation for mainstream Australia because of the much better control of diabetes in mainstream.

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Received 2 August 2010; accepted 2 August 2010.

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1. Clark A, Morgan WH, Kain S *et al.* Diabetic retinopathy and the major causes of vision loss in Aboriginals from remote Western Australia. *Clin Experiment Ophthalmol* 2010; **38**: 475-82.
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### Diabetic retinopathy in Australian Aboriginal people: response

We thank Professor Taylor for his comments<sup>1</sup> regarding our paper.<sup>2</sup> We presented 12 years of data from the Goldfields Eye Health Survey which consisted of yearly visits to the Eastern Goldfields Aboriginal communities between 1995 and 2007. The survey represents one of the longest running Aboriginal eye health initiatives in Australia and allows a unique insight into Australian Aboriginal eye health over time that cannot be gleaned from cross-sectional community surveys. Although we did not examine all of the over 4000 Aboriginal people living in the region, we do feel that the 920 seen comprised at least the major proportion of those with vision problems or who were diabetic.

Our yearly visits to Aboriginal communities in the Eastern Goldfields region are in line with the frequency of eye examination for Aboriginal people with diabetes recommended in the National Health and Medical Research Council Guidelines on diabetic retinopathy.<sup>3,4</sup> We should clarify that in commenting upon the poor follow-up of those Aboriginals examined it was our intention to emphasize this by comparing follow-up to the minimum standard for the general Australian population (2 years). That only 47.9% of those with diabetes were seen again within 2 years falls vastly short of the minimum recommendation for even the general Australian population. We did not intend to imply that the recommended screening interval for Aboriginal and Torres Strait Islanders be 2 years and appreciate the opportunity to provide further clarification.

Our data were collected in consistent, low-cost manner over many years and demonstrates the utility of creating a prospective Aboriginal eye disease registry. This is particularly important for diabetes, where retinal disease grades can be stored and retrieved. A national or state-wide scheme storing retinal photograph and/or clinical examination scores, dates and locations would be a cost-effective way to check individual follow-up status, disease severity as well as trends in disease.

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Received 26 August 2010; accepted 17 September 2010.

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Ng, J. Q., Morlet, N., **Clark, A.** and Taylor, H. R. (2011), **Referral of diabetic macular oedema by Australian optometrists: response.** *Clinical & Experimental Ophthalmology*, 39: 924.

question the NH&MRC guidelines rather than the optometric practices of Australian optometrists. Member feedback suggests the general view of optometrists and many ophthalmologists is that patients presenting with mild DR without DME can be managed by optometrists and should be referred in a timely fashion when the optometrist finds referral necessary.

The association advises all optometrists to discuss management of patients with mild NPDR without DME with their local (or visiting) ophthalmologist and to take advice as to the appropriate management protocol in these cases.

**Jared Slater BOptom and Joe Chakman BSc**  
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Received 11 July 2011; accepted 15 July 2011.

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## Referral of diabetic macular oedema by Australian optometrists: response

We thank Slater and Chakman for their interest in our survey.<sup>1</sup>

Given the interest and debate that was generated by our findings, it is good to see that a further on-line survey has

*Conflict/competing interest:* None declared.

*Funding sources:* None declared.

been conducted. With the relatively low response rate of 26% it would be easy to over interpret their results. Nonetheless, it is still worrying that 17% of optometrists would not always refer a patient with diabetic macular oedema for further assessment and treatment by an ophthalmologist even if they only had otherwise minimal non-proliferative diabetic retinopathy.

This would indicate a critical deficiency of knowledge, which is further reinforced by the fact that according to Slater and Chakman, some optometrists may have misinterpreted our use of 'not clinically significant' as inferring not needing referral. Further the fact that the National Health and Medical Research Council guidelines on diabetic retinopathy<sup>2</sup> had only been read by 65% clearly demonstrates that more can and should be done to improve the management and timely referral of patients with retinopathy.

Like all health professionals, optometrists need to fully embrace a culture of continuing education and quality improvement. All relevant stakeholders need to foster continuing education and work to ensure all professionals involved with diabetic retinopathy screening are suitably informed.

**Jonathon Q Ng MBBS PhD<sup>1</sup>, Nigel Morlet FRANZCO<sup>1,2</sup>, Antony Clark MBBS(Hons)<sup>1</sup> and Hugh R Taylor AC FRANZCO<sup>3</sup>**

<sup>1</sup>*Eye and Vision Epidemiology Research Group, School of Population Health, The University of Western Australia,*

<sup>2</sup>*Department of Ophthalmology, Royal Perth Hospital, Perth, Western Australia, and* <sup>3</sup>*Melbourne School of Indigenous Health, The University of Melbourne, Melbourne, Victoria, Australia*

Received 29 July 2011; accepted 31 July 2011.

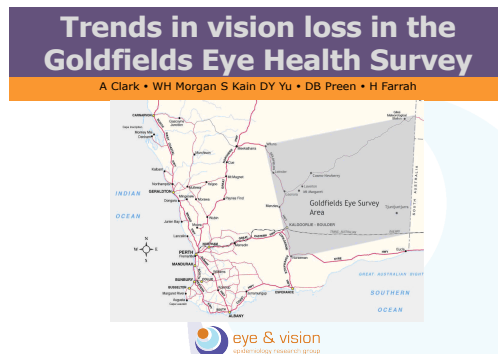
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## **4.5. Conference presentations**

# 40th Annual Royal Australian and New Zealand College of Ophthalmologists Annual Scientific Conference, Melbourne, Australia, November 2008.

**Free paper: Clark A, Morgan WH, Kain S, Farrah H, Preen DB, Yu DY. Trends in vision loss in the Eastern Goldfields Eye Health Screening Survey 1995 to 2007.**



## Participant characteristics

**Table 1.** Characteristics of Aboriginals (>16yrs) seen in the Eastern Goldfields Eye Health Survey 1995 to 2007

	All participants (n=920)	Diabetics (n=329)	P-value <sup>1</sup>
<b>Examinations (n)</b>	1,331	660	
<b>Age (years)<sup>2</sup></b>			
Male (mean±SD)	43.1 ± 15.0	48.5 ± 12.2	< 0.0001
Female (mean±SD)	40.7 ± 14.7	47.7 ± 13.4	< 0.0001
<b>Female (n, %)</b>	500 (54.4)	195 (59.3)	0.05
<b>Remote community (n, %)</b>	520 (56.5)	221 (67.2)	< 0.001
<b>Vision Loss (n, %)<sup>3</sup></b>			
Monocular VI	159 (17.3)	121 (36.8)	< 0.001
Monocular blindness	88	70	
Bimocular VI	24	22	
Bimocular blindness	79	57	

<sup>1</sup> P-values are derived from student's t-test for continuous variables and chi-squared test for categorical variables comparing the diabetic to non-diabetic population.  
<sup>2</sup> Age was only available for 595 participants.  
<sup>3</sup> Persons may contribute to more than one category over the study period.

## Cause of vision impaired/blind eyes

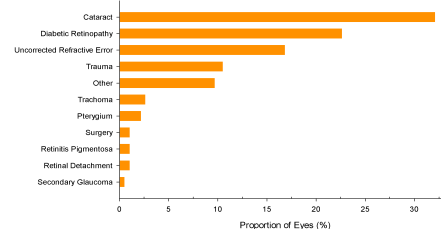
**Table 2.** Known causes of blind and vision impaired (VI) eyes in Aboriginals examined in the Eastern Goldfields Eye Health Survey 1995 to 2007<sup>1</sup>

Cause	VI eyes n (%)	Blind eyes n (%)	Total eyes <sup>2</sup> n (%)
Cataract	42 (28.6)	16 (38.1)	53 (30.1)
Diabetic retinopathy	42 (28.6)	7 (16.7)	44 (25.0)
Refractive error	31 (21.1)	0 (0.0)	31 (17.6)
Trauma	8 (5.4)	13 (31.0)	19 (10.8)
Other	10 (6.8)	3 (7.1)	12 (6.8)
Trachoma	3 (2.0)	1 (2.4)	4 (2.3)
Pterygium	4 (2.7)	0 (0.0)	4 (2.3)
Amblyopia	2 (1.4)	1 (2.4)	3 (1.7)
Retinal detachment	2 (1.4)	0 (0.0)	2 (1.1)
Retinitis pigmentosa	2 (1.4)	0 (0.0)	2 (1.1)
Secondary Glaucoma	0 (0.0)	1 (2.4)	1 (0.6)
Surgical Complication	1 (0.7)	0 (0.0)	1 (0.6)
<b>Total</b>	<b>47 (100)</b>	<b>147 (100)</b>	<b>176 (100)</b>

VI = 6/12; 26/60; Blind = 6/60

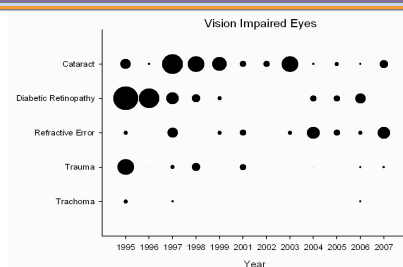
<sup>1</sup> The cause of vision loss was not recorded for 70 eyes (3 VI eyes, and 68 blind eyes).  
<sup>2</sup> Eyes may contribute to more than one category over the study period e.g. VI eyes that have progressed to blindness.

## Cause of vision impaired/blind eyes



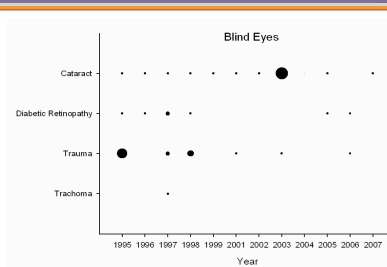
## Trend Over Time

### Vision Impaired eyes (VA < 6/12)



## Trend Over Time

### Blind eyes (VA < 6/60)



## Diabetic retinopathy in Aboriginals with diabetes

**Table 4.** Proportion of diabetics seen with diabetic retinopathy (DR) and vision-threatening retinopathy (VTR) in other Aboriginal communities.

Author	Location	Year	DR	VTR
Durkin et al. <sup>11</sup>	Remote, South Australia	1999 - 2004	21%	12%
Murray et al. <sup>12</sup>	Kimberly region, Western Australia	1999 - 2004	21%	3.5%
Diamond et al. <sup>13</sup>	Pilbara region, Western Australia	1997	23%	-
Jaross et al. <sup>10</sup>	Katherine region, Northern Territory	1996	21%	8.5%
		1993	18%	6.7%
<i>Our study</i>	<i>Goldfields region, Western Australia</i>	<i>1995 - 2007</i>	<i>25%</i>	<i>9.7%</i>

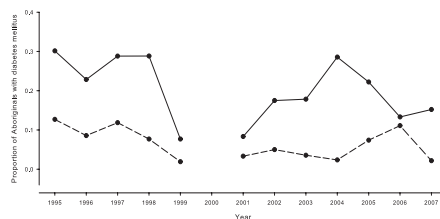
## Diabetic retinopathy in Aboriginals with diabetes in the Goldfields

**Table 3.** Severity of diabetic retinopathy in Aboriginals with diabetes seen in the Eastern Goldfields Eye Health Survey 1995 to 2007 (n (%))

	n	DR	Severity of Diabetic Retinopathy					
			Macula Oedema		NPDR			VTR
			CSME	DMENS	Mild	Mod	Severe	
<b>1995-1997</b>	152	44 (28.9)	14 (9.2)	7 (4.6)	21 (13.8)	13 (8.6)	4 (2.6)	3 (2.0)
<b>1998-2001</b>	156	24 (15.4)	6 (3.8)	6 (3.8)	11 (7.1)	6 (3.8)	2 (1.3)	0 (0.0)
<b>2002-2004</b>	131	29 (22.1)	2 (1.5)	7 (5.3)	20 (15.3)	3 (2.3)	4 (3.1)	0 (0.0)
<b>2005-2007</b>	118	19 (16.1)	7 (5.9)	2 (1.7)	7 (5.9)	6 (5.1)	4 (3.4)	1 (0.8)
<b>Total</b>	329	82 (24.9)	27 (8.2)	20 (6.1)	40 (14.2)	24 (7.3)	13 (4.0)	3 (0.9)
<b>At first visit</b>	329	60 (18.2)	19 (5.8)	8 (2.4)	31 (9.4)	15 (4.6)	6 (1.8)	2 (0.6)

DR = diabetic retinopathy, NPDR = non-proliferative diabetic retinopathy, CSME = clinically significant macular oedema, DMENS = diabetic macular oedema not significant, PDR = proliferative diabetic retinopathy, VTR = vision-threatening retinopathy (CSME or severe NPDR or PDR).

## Trend in diabetic retinopathy among Aboriginals with diabetes



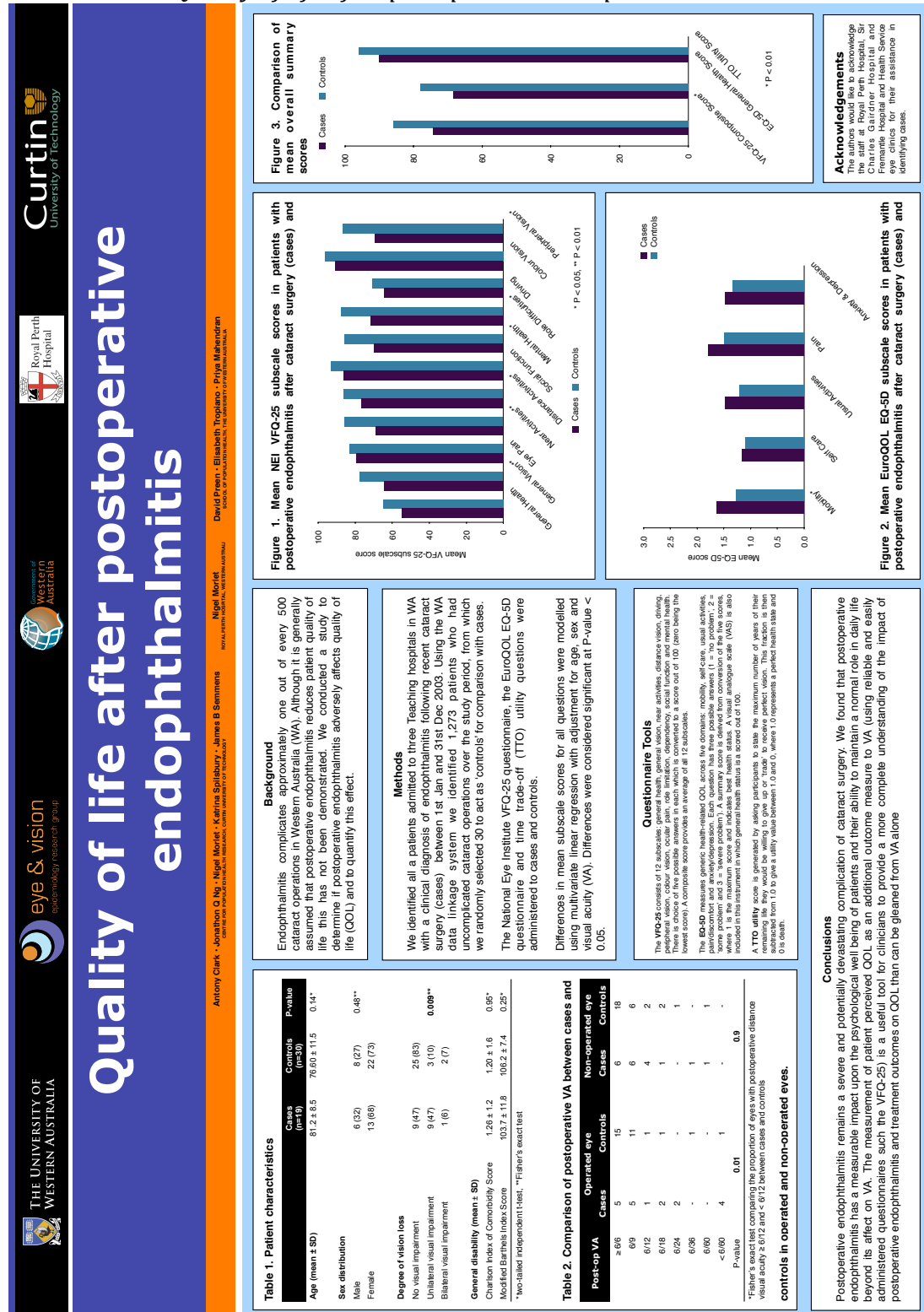
**Figure 3.** Trend in the proportion of adult Aboriginals with diabetes with diabetic retinopathy seen in the Eastern Goldfield Eye Health Survey 1995 to 2005. (—), any diabetic retinopathy; (---), vision threatening retinopathy (VTR). (No survey was conducted in 2000).

## Main findings

- Major four causes of vision loss in Goldfields Aboriginals are **preventable**
- **Diabetic retinopathy** a major problem Requires a coordinated approach!
- No new **trachoma** blindness since 1997
- **Trauma** is an important cause of monocular blindness
- No primary **glaucoma** cases of visual impairment or blind

# World Ophthalmology Congress, XXI International Congress of Ophthalmology, Hong Kong, China, June 28 - July 2, 2008

Poster: Clark A, Ng JQ, Morlet N, Spilsbury K, Semmens JB, Tropiano E, Mahendran P. *Quality of life after postoperative endophthalmitis*



## **Chapter 5**

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### **Discussion**

## **5.1. Key findings and their clinical significance**

Western Australia is ideal for population-based research that is representative of Australia. Despite its isolation and comprising only one-tenth of the national population it is among the three jurisdictions closest to the eight-jurisdictional average in all but two socioeconomic and demographic indicators (proportion privately insured and per capita health expenditure). It also has one of the highest proportions of the population who are Aboriginal, making it better suited than other jurisdictions to population-based research involving Aboriginal health issues. In comparing the population profiles of Australia's State and Territory populations, researchers are better able to determine the extent to which contextual issues concerning key socio-demographic and health economic indicators may affect the external validity of research results arising from any one jurisdiction. These findings lend support to the notion that any key findings arising from this thesis are externally valid to the wider Australian context.

The major projects presented in this thesis encompass six broad themes concerning blinding eye diseases in WA i.e. cataract surgical safety and outcomes, ARMD medication safety/post-marketing surveillance, epidemiology of blindness, Aboriginal and remote eye health, diabetic retinopathy screening and management, and quality of life. In carrying out these projects the strengths and limitations in using hospital administrative data for health research were explored, as well as alternative methodologies that may augment or supplement the information available in them. The major findings from these projects will now be discussed.

### ***Cataract surgery complications***

A significant part of this thesis was dedicated to understanding the trends and impact of blinding complications of cataract surgery in WA. Cataract surgery is one of the most common operations performed in WA and rates have increased linearly over the study period. Patients may continue to be reassured that cataract surgery is safe - less than 1% of procedures result in a serious sight-threatening complication in WA. The trend is towards improving safety since

the transition to phacoemulsification from ECCE, where the rate of postoperative complications has declined by over 70% over 21 years.

Retinal detachments are the most common serious complication (5-year cumulative incidence 0.63%) and have not been affected adversely by the transition to phacoemulsification from ECCE (RR=1.00, 95% CI 0.82-1.23). Significant population-based risk factors for the occurrence of retinal detachment after phacoemulsification in particular were male gender, younger age, and anterior vitrectomy being performed during cataract surgery.

Wound dehiscence is predictably far less common since the introduction of small incision phacoemulsification surgery with rates nearly one-tenth of that seen in ECCE (RR=0.12, 95% CI 0.08-0.18). Dropped nucleus is still rare but increased significantly when phacoemulsification was introduced (IRR=1.74 for each 5 year period since 1990 95%CI 1.16-2.63) for both phacoemulsification and ECCE. While IOL dislocations were uncommon, rates have almost doubled during 1985 to 2001 (0.17 to 0.30 per 1,000 procedures), which warrants further scrutiny. Pseudophakic corneal oedema is very uncommon and has declined significantly.

The rate of complicated cataract surgery needing anterior vitrectomy has also declined since the 1980s and is a good indication of improved surgical safety. Major risk factors for its occurrence were older or younger age, male gender, and surgery performed in public and rural/remote hospitals. The risk for serious sight-threatening complications is increased significantly if it occurs, particularly for retinal detachment and IOL dislocations.

The degree to which these serious complications may impact quality of life was explored in postoperative endophthalmitis patients and was one of the first studies to do so. Postoperative endophthalmitis causes a significant reduction in quality of life across multiple domains in three validated quality of life instruments. This most significant in the National Eye Institute VFQ-25 tool where patients reported a significant impact on general vision, near activities, mental health, role difficulties and peripheral vision. This information is particularly important since it demonstrated the added burden of serious



adverse cataract surgery outcomes beyond what can simply be reported using health administrative data.

The body of knowledge regarding cataract surgery complications generated in this PhD arms ophthalmic surgeons in WA and wider afield with the information to appropriately counsel their patients regarding the likely risk of a serious complication during and following their cataract surgery. It also supports clinical decision making by allowing them to identify which of their patients are at particularly high risk for a serious complication during and following surgery (like retinal detachment) and to monitor those patients accordingly in the postoperative period. While serious complications are rare and becoming even more so, large numbers of surgeries mean even rare complications have the potential to cause significant visual morbidity in the community. It is therefore imperative to continue to monitor and improve the safety of cataract surgery (particularly with the advent of new technologies into the future) if this morbidity is to be minimised.

***Post-marketing surveillance: anti-VEGF for ARMD***

While procedures such as cataract operations are well coded in hospital administrative databases, off-label medications are not. This study demonstrated the utility of adhoc linkage of clinic electronic medical records and registries to administrative data to study rare adverse outcomes of novel treatments.

The introduction of intravitreal anti-VEGF for WA patients with neovascular ARMD has revolutionised their care without having a major impact on their risk of thromboembolic events. The risk of stroke or gastrointestinal bleeding associated with intravitreal anti-VEGF use is not significantly more than that seen in the community and, while the rate of myocardial infarction is over double seen in community, the absolute increase in risk remains low (1.9% vs 0.7%).

On a whole-population level, the widespread uptake of anti-VEGF treatment for neovascular ARMD (and more recently for vein occlusion and diabetic maculopathy) has the potential to produce a significant additional burden for the WA health system due to the increased number of myocardial infarcts. This

must be weighed against its effectiveness as the only treatment to slow or prevent blindness that, on an individual level, potentially outweighs the relatively small increased risk of heart attack. However, as newer agents are developed, then comparing the risk of adverse thromboembolic events between these agents will become more important in guiding patient safety.

#### ***The epidemiology of blinding eye disease***

EBEDS has taught us a great deal about blindness in WA. Capture-recapture methodology has proven itself to be useful in providing a reasonably efficient and cost-effective way to estimate blindness prevalence in the community. We estimated 3,384 (95% CI 2,247 to 3,983) or 0.15% of the population were legally blind in WA at 30<sup>th</sup> September 2009. Our results were comparable to those from other Australian population-based surveys - the Blue Mountains Eye Study and the Melbourne Vision Impairment Project, which found approximately 0.5% of those aged 50 years or older, were blind.<sup>13,15</sup>

These findings demonstrate that government and community support agencies are unaware of a significant proportion of those who are legally blind in the community. Our number exceeded the number of people in WA registered for the blind pension or registered with the Association for the Blind (ABWA) – the states only provider of vision rehabilitation and support services. ABWA maintains a large (n=4,272) dataset of vision impaired and legally blind people in WA that is reasonably precise for identifying legal blindness (sensitivity 75%, specificity 60%) and with reasonable diagnostic accuracy. Yet only 40% of those legally blind are registered with the service, leaving 60% of the legally blind community in WA without rehabilitation support. Aboriginals were even less likely to be represented with only 17 actually registered despite large surveys suggesting 1.9% of the Aboriginal population are likely to be legally blind.<sup>323</sup>

Blindness is important since we found that it results in more hospital admissions; longer hospital stays, and increased mortality for those children and working age people in WA who are blind. Blindness is also associated with a significant reduction in quality of life with the greatest reduction at the cut-off to legal blindness (logMAR >1).

The development of a validated blind register that is inclusive of the majority of blind people in WA is a future goal and would provide a useful resource for further linked data studies. Ongoing linkage with the WADLS would allow a hard endpoint be identified in blinding eye diseases and also the study of health outcomes of the blind cohort. This would have particular relevance to the evaluation of rehabilitation services provided by ABWA and others for the blind and vision impaired.

#### ***Australian Aboriginal Eye Health***

EBEDS taught us that the blind Aboriginal population are poorly represented in the ABWA register and, even with capture-recapture methods; the vastness of WA makes identifying them difficult. Data collected during the clinics of the eastern Goldfields eye health survey provided a unique opportunity to better understand the causes and patterns of vision loss in these communities, and particularly diabetic retinopathy. The results indicated that the state of eye health in Aboriginals from the remote eastern Goldfields region of WA remains a concern. The top three causes of vision loss in these communities (cataract, diabetic retinopathy, and refractive error) are preventable and/or readily treated. We should not still be seeing cataract-related blindness (30% of all blind eyes in the survey), which combined with high rates refractive error in these communities points to significant barriers in access to ophthalmic care. Diabetes in particular has a significant association with vision loss and blindness, yet screening of diabetics in these communities remains suboptimal. Of some reassurance in this survey was the low level of trachoma-related vision loss – although this particular survey didn't capture the current level of active trachoma in the community.

Findings from this survey were presented to local ophthalmologists and also nationally and supported the impetus for change. Since publication, significant changes to the delivery of ophthalmic care have occurred culminating in the development of the Lions Outback Vision initiative in 2010. This initiative was established in response to the recognised inadequacy of eye care provision in remote WA indigenous communities with the specific aim to address the

“unique challenges of delivering quality specialist eye health care to regional, remote and Indigenous communities across the state”.<sup>364</sup>

#### ***Diabetic retinopathy screening and management practices***

This national survey provided important insights into the state of eye care provided by ophthalmologists, optometrists and GPs across the country for the rapidly growing population of diabetics Australia. There is a declining trend in the desire of ophthalmologists and GPs to participate in community diabetic retinopathy screening. GPs lack the confidence to detect signs of diabetic retinopathy and don't have the time to perform a dilated retinal exam, despite a good level of knowledge regarding appropriate screening and management protocols. Optometrists demonstrated the greatest motivation for screening, are better equipped than GPs in being able to provide this service, and are more confident in detecting signs of diabetic retinopathy. However, further education is needed to improve knowledge among optometrists since over-screening and under-referral is an issue. Of most concern was that the majority of optometrists aren't confident in detecting macular oedema and a significant proportion reported they (inappropriately) do not refer macular oedema for ophthalmology review. Ophthalmologists generally adhere well to best practice guidelines for screening and management of diabetic retinopathy. Areas for improvement included over-screening of pre-pubertal diabetics and over-use of fluorescein angiography. Those who were further from their training years were most likely to deviate from best practice guidelines.

Feedback of these findings to the optometry, ophthalmology and GP community included publication in national medical journals, presentation at the national ophthalmology college congress, and media releases in the optometry and GP communications. The optometry findings in particular stimulated discussion within the optometry community where there was consideration for further education.

## **5.2. Strengths and limitations**

The strengths and limitations specific to the individual studies are discussed in greater detail in the discussion section of each of the papers. The following

provides a discussion of the broad strengths and limitations of the work presented in this thesis.

A significant portion of this research was population-based, using large administrative databases from a stable, isolated population that is representative of Australia. This ensured large sample sizes, almost complete case ascertainment with minimal loss to follow-up within the state, and findings that were externally valid to the wider-Australian context. The large sample sizes were essential for studying rare events i.e. cataract surgery complications and thromboembolic events after anti-VEGF treatment particularly when multiple risk factors were examined. They allowed large multivariate models that controlled for multiple risk factors and potential confounders simultaneously.

The limitations of studies using administrative databases relate to their retrospective observational design, the effect of confounding by variables not present in the databases or not accounted for in the analysis (e.g. medication use, lifestyle factors, ocular biometry) and issues with quality data. These issues were discussed in greater detail in Chapter 1. Perhaps the greatest limitation of administrative databases are the lack of clinical detail in the variables recorded, which severely limits the scope of clinical questions that may be answered. This was demonstrated by the fact that both projects in this thesis that used administrative databases required some form of data validation (e.g. confirming laterality) or additional data be sought (e.g. type of anti-VEGF given or cataract surgery operative details). This also slows research considerably, particularly when chart review is required. The cataract surgery complications project took several years before data validation was complete due to the sheer volume of charts that needed manual review.

To strengthen and broaden the scope of the clinical story of eye care outcomes in WA beyond what could be provided in administrative data, other epidemiological methods were explored. Understanding the impact on quality of life of a serious complication of cataract surgery, such as postoperative endophthalmitis and of severe vision impairment, is essential if we are to accurately quantify its importance beyond a fairly superficial focus on health

outcomes as they relate to cost and health service utilisation. Loss of quality of life is costly and through calculation of utility values and quality-adjusted life years, can be quantified.

The unique survey of blind and near blind people in WA allowed the development of a well validated group upon which to conduct further studies of their health outcomes and service utilisation. The capture-recapture methodology used to provide an estimate of prevalence of blindness in WA compared favourable with results from large Australia cross-sectional surveys. It demonstrated this methodology to be an efficient and cost effective way to estimate blindness prevalence.

Clinical surveys also offered greater insight into clinician knowledge, and attitudes regarding diabetic retinopathy screening and management. There is concern among some that the focus on health outcomes as a driver of quality care neglects the 'art' of medicine, ignoring the inherent uncertainty and vagaries of disease that clinicians are presented on a daily basis.<sup>365</sup> Focusing purely on research utilising administrative databases will tell us what was actually done (to an extent) but tells us nothing regarding the 'why' or 'why not'; nor does it inform us about a clinicians level of knowledge or understanding that underpins their practice. While we may easily discover where there are deficiencies in care, without this knowledge it is not possible to know where or how changes could be made. The major limitations in this survey were selection, reporting and recall bias that limits external validity. This was a particular issue in surveys sent to general practitioners where response rates were very poor (21%).

Similarly, data from the clinical register of the eastern Goldfields eye health survey provided a comprehensive overview of the state of diabetes and burden of vision impairment in an isolated, vulnerable population otherwise not captured in routine hospital administrative databases in WA. The long duration of the eye health survey meant that those with vision problems and/or diabetes should have been captured at least once, unlike in previous cross-sectional studies in Australia.

## **5.3. Research translation**

### **5.3.1. Dissemination of research findings**

Research arising from this thesis has been the subject of a comprehensive dissemination strategy at a local, national and international level. At a local level, this has involved reporting of research findings to WA ophthalmologists at hospital clinical meetings as well as WA Royal Australian College of Ophthalmologists (RANZCO) clinical meetings. In addition to being a training ophthalmologist myself, the clinical advisory team on the projects comprising the thesis are local ophthalmologists. This meant there was a direct feedback of research findings to the local clinical ophthalmology community and thus a direct translation into clinical practice. This has facilitated an effective and rapid completion of the research feedback loop.

At a national level, the findings from these projects were presented at the RANZCO annual scientific congresses in the form of talks and poster presentations. Publication of these findings in the national medical journals ensured feedback to the wider Australian medical community. While internationally, research findings were presented at the World Ophthalmology Congress in Hong Kong as well as in high-ranking international ophthalmology journals.

### **5.3.2. Future projects**

The expertise developed in this thesis and the anti-VEGF project in particular will support a new study to evaluate the benefit in delaying the progressing from vision impairment to blindness associated with the introduction of the anti-VEGF treatments for ARMD. Linking blind registration data with hospital morbidity and mortality data will allow the impact of treatment for ARMD on patient morbidity (e.g. hospital admissions, falls) and mortality to be measured. In doing so, the cost savings produced by the reduction in new blind registrations can be quantified.

Other promising population-based projects that have arisen as a result of the knowledge and expertise generated through this thesis include studies of glaucoma and crash risk through linkage of automated perimetry (visual field)

data with hospital morbidity and road traffic datasets; trends in eye care service utilisation through the linkage of outpatient eye clinic attendance data with hospital attendances; and the population-based risk for retinal detachment in WA.

An exciting and promising application of data linkage techniques is the use of Australia's Commonwealth health datasets for health research. Two major datasets include the Pharmaceutical benefits scheme (PBS), which includes all prescriptions funded by the federal government; and Medicare, which includes patient attendances to general practice and specialist clinics outside of public hospitals. Three major projects were initially conceived as part of this thesis: one project to identify and describe the WA glaucoma population and their treatment trends using prescriptions for eye drops and admissions for surgery; another to describe the use and adequacy of diabetic retinopathy screening using Medicare attendances to ophthalmologists and other eye care providers; and the third to characterise the trends in eye care services utilisation using Medicare data from attendances to eye care providers. However, despite a memorandum of understanding being in place between the WALDS and the Commonwealth agencies involved, there were lengthy delays and eventually an inability of the Commonwealth to supply the data for these projects, and so they could not be completed.

These projects still represent important health priority areas for ophthalmic research in Australia. There is also the potential to support a vast program of ophthalmic research through data integration processes into areas that determine social and economic determinants of health such as educational and welfare records. The impact of ophthalmic disease on other health outcomes e.g. injury and mental health may be usefully assessed with data integration.

The expertise in population-based health research developed during this thesis along with the establishment of the PHRN is a promising step towards seeing these projects to fruition.



### **5.3.3. Automating data collection and extraction**

#### ***The electronic cataract audit tool (eCAT)***

The ability to undertake population-based research that supports real-time monitoring of adverse outcomes and trends in disease in a timely manner is an exciting reality for the future of health research. This can be attributed to the methodologies developed to analyse very large pre-existing datasets. The implementation of the eCAT system (Appendix 3) in hospitals across WA will be instrumental in facilitating population-based monitoring of cataract surgery outcomes in a timely fashion by facilitating the collection of more accurate and complete cataract surgery data. Automated integration with the WADLS is envisioned for the future and will eliminate the time and costs required for chart review and pave the way for outcomes research that is more contemporary and thus more relevant for the ophthalmology community.

The system is currently available for use in all public hospitals (the major tertiary hospitals have mandated its use) and a major private facility in Perth has also adopted the system. The next phase of the project will be the development of pre- and post-operative modules that will add further utility to the system. Its success has led to interest from clinicians in sub-speciality areas to develop similar modules to address operations in their areas e.g. glaucoma surgery or retinal detachment surgery since the eCAT system is flexible enough that it can feasibly be adapted to any ophthalmic procedure.

The future vision for the eCAT system is to provide real time reporting of complication risk and monitoring of risk events for timely surgeon feedback. Analysis already undertaken on cataract surgery complications in WA since 1980 provides a robust dataset that allows calculation of prior probabilities upon which Bayesian techniques may be applied to generate risk models and upon which real time reporting of complication risk may be achieved.<sup>366</sup>

#### ***Clinical registries***

Purpose built clinical registries aggregated by scraping data from electronic health records (EHR) offers a practical and efficient solution to address limitations in hospital administrative data and traditional clinical registries. For example, the American Academy of Ophthalmology's newly commissioned IRIS

Registry (Intelligent Research in Sight) offers the promise of a national comprehensive eye disease register. It is designed to assist in delivering quality patient care through measuring and reporting outcomes and bench-marking.<sup>367</sup> A breakthrough in the design of the registry was its integration with physician EHR that avoids disruption of physician workflow and duplicate data entry that are major barriers to the implementation and ongoing success of clinical registries.<sup>367</sup> In Australia, there needs to be a greater political imperative coupled with improved design and ergonomics of EHR's to see their use expand throughout the wider ophthalmic community and achieve what is being attempted in the US.

Methods are also required to utilize the existing information held electronically as text files outside modern HER, as there is a huge amount of legacy data stored since the advent of word-processors (e.g. consultation letters). That information would provide further important historical data to assess trends in diagnosis and management. Such techniques may also enable integration of written reports from other areas such as pathology and radiology.

#### ***The 'Big Data' revolution***

As more data sources are created and data integration process allows the linkage of multiple data sources, then the volume of data available for research will continue to grow. This begs the question - how do you then deal with such massive amounts of data so called "Big data". Big data methodologies being developed allow the efficient study of large databases using machine learning algorithms that offer the promise of better predictive models, the ability to deal with non-validated 'dirty' data without the need for comprehensive data cleaning, and faster computing with more data.<sup>368</sup> It offers a practical solution that best capitalises on the vast volume of data likely to be generated as more EHR and clinical registries come online. Developing greater expertise in this area for health will be imperative if we are to take full advantage of the benefits that may be delivered through big data trends currently occurring outside of health.

## **5.4. Personal and professional development**

### **5.4.1. Professional development**

This PhD programme has equipped me with the skills and maturity necessary to go on to further develop my interests in clinical research. On a practical level I have gained expertise in developing comprehensive research protocols and proposals, interacting with human research ethics bodies to ensure research is carried out in an ethical way, performing complex analysis of large administrative datasets, and the development of grant applications for funding of ongoing research. I also undertook several courses to assist in my statistical analysis skills including introductory and advanced courses in the analysis of linked health data, a unit in biostatistics, and a course in data management using SAS software.

### **5.4.2. Clinical training**

During the PhD programme I completed my clinical training in ophthalmology. The knowledge gained through the projects comprising this PhD has helped shaped my clinical practice by providing the evidence base necessary to support my day-to-day clinical decisions. For example, using knowledge of cataract surgery complications in WA I am better able to inform patients regarding their specific risk for adverse events; while I have a better understanding of the unique eye health challenges facing our blind and our local remote Aboriginal populations. Similarly, the clinical knowledge developed during clinical training has contributed to shaping the thesis, particularly in my understanding of cataract surgery outcomes and in contextualising the importance of the research. For example, ‘dropped nucleus’ is not simply a word in a table, for me it is an 88-year-old grandmother of 15 with pseudoexfoliation who spent many days of her life in an ophthalmology clinic, undergoing multiple procedures due to her complicated cataract operation that left her legally blind. Through my clinical work I am also better able to identify the gaps in our clinical knowledge and thus direct my future research interests.

### **5.4.3. Vision for the future**

As I write the final words in this thesis I look towards a new phase in my career. I have commenced a year-long clinical fellowship in glaucoma and anterior segment surgery in Toronto, Canada; and will follow this with another in paediatric ophthalmology. My vision is to continue on with my research interests in ophthalmic epidemiology and outcomes research whilst in Canada and foster collaborative links with researchers in Canada that I may nurture on return to Australia.

While I will maintain my strong commitment to clinical ophthalmology I would like to see my clinical practice complemented and rounded off with a productive research portfolio. This would include working within the framework of our current collaborative research team in WA as part of the eye and vision epidemiology research group (EVER group). I can envision the EVER group developing further as an enthusiastic group of engaged clinicians and researchers interested in ophthalmic epidemiology. I would like to support the EVER group collaboration develop further into a research body that supports research fellows, higher degree by research students and other clinicians with an interest in epidemiology; while allowing it to be productive in securing competitive research grants that allow us to undertake internationally competitive research.

I see a real need for ongoing research into surgical outcomes in ophthalmology and in particular the development of real-time monitoring of outcomes and adverse events. We rely too heavily on published studies, often of events that have occurred years ago somewhere else. The future of health is in EHR and we in WA are well placed to take advantage of this changing tide, particularly through the work we have already achieved in this area. I would personally like to see a future whereby surgeons are able to understand exactly where they are in terms of their surgical outcomes within a legal and political framework that fosters a 'no-blame' policy and supports reflective self-improvement. To achieve this in 'real-time', simply at the touch of a button is now a more achievable reality with big data techniques. I suspect the greatest challenge won't be in

developing the appropriate techniques and infrastructure, but rather in developing the legal and political framework that supports it.

This thesis has only explored the tip of a very large iceberg that represents the future possibilities for big data in ophthalmic research. I'm excited to be a part of the drive that will see us make best use of existing data for outcomes research that will improve our day-to-day clinical practice in a meaningful way.

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# Appendix 1: Ethics approvals



Government of **Western Australia**  
Department of **Health**

## HUMAN RESEARCH ETHICS COMMITTEE (DOHWA HREC) AHEC EC00422

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Dear Prof Semmens

**Project #2011/18**  
**Endophthalmitis and the Complications of Cataract Surgery 1980 to 2008**

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<b>Date of commencement:</b>	01/03/2011	
<b>Date of completion:</b>	Ongoing	
<b>Research Team:</b>	Prof James Semmens	Dr Antony Clark
	Dr Nigel Morlet	Dr Jonathon Ng
	Dr Katrina Spilsbury	Ms Julie Crew
	Ms Patricia Barrett	Mr Syed Mukhtar
	Delia Hendrie	Dr William Tjhin
	Emily Stanton	A/Prof Bill Morgan
	Dr Tina Khanam	Dr Daniel Ting
	Dr Charlotte McKnight	Dr Wayne Reynolds
<b>DOH data required:</b>	Yes	
<b>Data linkage required:</b>	Yes	
<b>Datasets to be accessed:</b>	Hospital Morbidity;	Mortality
<b>Date of Ethical Review:</b>	13/04/2011	
<b>Ethics approval validity:</b>	13/04/2015 (4years)	

---

I am pleased to advise that the Committee has granted **ethical approval** for this project.

This letter constitutes **Ethics Approval only**; you will not receive the data requested for your project until approval for the release of these data is signed by the Department of Health WA Director General's delegate.

This approval is subject to your continued compliance with the following conditions:

- DOHWA HREC holds the Principal Investigator responsible for the ethical conduct of the project and the security of the personal health information therefore he/she must -
  1. Report anything which might warrant review of ethical approval of the project in the specified format including:
    - Any serious or unexpected adverse events.
    - Unforeseen events that might affect the continued ethical acceptability of the project.
    - Submit for approval any changes or amendments to the research protocol, including methodology, data required, duration of the project and any changes to the approved data storage arrangements.

2. Advise if the project is discontinued or withdrawn before the expected date of completion and give reasons for this action.
3. Provide an annual progress report to the HREC and a final report at the completion of the project.
4. Advise any changes of personnel in the research team, and provide a DOHWA Confidentiality Agreement/Confidentiality Acknowledgement form for any addition to the research team.

We wish you well with your project.

Yours sincerely



Dr Judyth Allen  
Chair  
Department of Health WA Human Research Ethics Committee

19 April 2011

Cc Dr Antony Clark

DOHWA HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) 'National Statement on Ethical Conduct in Human Research'. Applications are also reviewed for compliance with the Department of Health WA 'Practice Code for use of personal health information'.





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Our Ref. RA/4/1/1905

24 September 2007

Dr D Preen  
School of Population Health - M431  
UWA

**HUMAN RESEARCH ETHICS COMMITTEE**

**Project:** Diabetic retinopathy screening and management practices of Australian  
general practitioners, optometrists and ophthalmologists  
**Student:** Joshua Shun Yuen - Masters - 19621708

Please be advised that ethical approval of the above project has been granted by the Human Research Ethics Committee.

The Committee is bound by NHMRC Guidelines to monitor the progress of all approved projects until completion to ensure that they continue to conform to approved ethical standards.

The committee requires that all Chief Investigators report **immediately** anything that might affect or impact upon ethical approval of the project, including adverse events affecting subjects.

Approval should be sought in writing **in advance** for any amendments to the original application. You are also required as a condition of this approval to inform the Committee if for any reason the research project is discontinued before the expected date of completion.

A report form for completion will be sent to you twelve months from this date or one month after your indicated completion date.

**Please note that approval has been granted for a period of four years. Initial approval is for a period of one year, and, thereafter for future periods of one year at a time subject to the receipt of satisfactory annual reports.** At the end of the four-year period you will be required to complete a new "Application to Undertake Research Involving Human Subjects" should you wish to continue with your research. However, in special circumstances, the Chair has the authority to extend the approval period in order to complete a project. **Failure to submit a final report may result in delays for future applications.**

**Please quote Project No RA/4/1/1905 all correspondence associated with this study.**

Yours sincerely

KATE KIRK  
Executive Officer  
(Human Research Ethics Committee)

cc: Dr Sato Juniper

App. Proj



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Our Ref. RA/4/1/2217

10 December 2008

Dr D Preen  
School of Population Health - M431  
UWA

#### HUMAN RESEARCH ETHICS COMMITTEE

**Project:** Does treatment of age-related macular degeneration with intravitreal injection of vascular endothelial growth factor inhibitors increase arterial thromboembolic events?

Please be advised that ethical approval of the above project has been granted by the Human Research Ethics Committee.

The Committee is bound by NHMRC Guidelines to monitor the progress of all approved projects until completion to ensure that they continue to conform to approved ethical standards.

The committee requires that all Chief Investigators report **immediately** anything that might affect or impact upon ethical approval of the project, including adverse events affecting subjects.

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A report form for completion will be sent to you twelve months from this date or one month after your indicated completion date.

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**Please quote Project No RA/4/1/2217 all correspondence associated with this study.**

Yours sincerely

KATE KIRK  
Executive Officer  
(Human Research Ethics Committee)

App. Proj



Government of **Western Australia**  
Department of **Health**

**HUMAN RESEARCH ETHICS COMMITTEE (DOHWA HREC)** AHEC EC00422

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Dr David Preen  
Director, Centre for Health Services Research  
School of Population Health (M431)  
The University of Western Australia  
35 Stirling Highway  
CRAWLEY WA 6008

Dear Dr Preen

**RE: Project #EC 2009/7**  
**Vascular Endothelial Growth Factor Inhibitors and Cardiovascular Events in**  
**Treatment of Neovascular Age-Related Macular Degeneration (VICE)**

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<b>Date of commencement:</b>	01/02/2009	
<b>Date of completion:</b>	31/12/2011	
<b>Research Team:</b>	Dr David Preen	Prof James Semmens
	Dr Frank Sanfilippo	Dr Tom Briffa
	Dr Antony Clark	A/Prof Nigel Morlet
	Dr Jonathon Ng	Dr Alexandra Bremner
	Dr Tina Khanam	Dr Charlotte McKnight
	Dr Wayne Reynolds	
<b>Data linkage required:</b>	Yes	
<b>Datasets to be accessed:</b>	Hospital Morbidity Data Collection Electoral Roll Mortality	
<b>Date of Ethical Review:</b>	11/02/2009	
<b>Ethics approval validity:</b>	11/02/2013 (4years)	

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I am pleased to advise that the Committee has granted ethical approval for this project.

Please note there was discussion amongst the Committee about whether patients are made aware of potential adverse effects of prescribed drugs. In the light of this discussion the Committee would like to know how the researchers intend to disseminate and communicate their findings (*National Statement on Ethical Conduct in Human Research* [Section 1.3(d)]).

This letter constitutes **Ethics Approval only**; you will not receive the data requested for your project until approval for the release of these data is signed by the Department of Health WA Director General's delegate.


This approval is subject to your continued compliance with the following conditions:

- DOHWA HREC holds the Principal Investigator responsible for the ethical conduct of the project and the security of the personal health information therefore he/she must -

1. Report anything which might warrant review of ethical approval of the project in the specified format including:
  - Any serious or unexpected adverse events.
  - Unforeseen events that might affect the continued ethical acceptability of the project.
  - Submit for approval any changes or amendments to the research protocol, including methodology, data required, duration of the project and any changes to the approved data storage arrangements.
2. Advise if the project is discontinued or withdrawn before the expected date of completion and give reasons for this action.
3. Provide an annual progress report to the HREC and a final report at the completion of the project.
4. Advise any changes of personnel in the research team, and provide a DOHWA Confidentiality Agreement/Confidentiality Acknowledgement form for any addition to the research team.

We wish you well with your project.

Yours sincerely



Dr Judyth Watson  
Chair  
Department of Health WA Human Research Ethics Committee

13 February 2009

DOHWA HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) 'National Statement on Ethical Conduct in Human Research'. Applications are also reviewed for compliance with the Department of Health WA 'Practice Code for use of personal health information'.



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Our Ref. RA/4/1/2266

22 April 2009

Dr D Preen  
School of Population Health - M431  
UWA

#### HUMAN RESEARCH ETHICS COMMITTEE

**Project: Monitoring cataract surgery outcomes in Western Australia: establishing a State-wide cataract surgery register**

Please be advised that ethical approval of the above project has been granted by the Human Research Ethics Committee.

The Committee is bound by NHMRC Guidelines to monitor the progress of all approved projects until completion to ensure that they continue to conform to approved ethical standards.

The committee requires that all Chief Investigators report **immediately** anything that might affect or impact upon ethical approval of the project, including adverse events affecting subjects.

Approval should be sought in writing **in advance** for any amendments to the original application. You are also required as a condition of this approval to inform the Committee if for any reason the research project is discontinued before the expected date of completion.

A report form for completion will be sent to you twelve months from this date or one month after your indicated completion date.

**Please note that approval has been granted for a period of four years. Initial approval is for a period of one year, and, thereafter for future periods of one year at a time subject to the receipt of satisfactory annual reports.** At the end of the four-year period you will be required to complete a new "*Application to Undertake Research Involving Human Subjects*" should you wish to continue with your research. However, in special circumstances, the Chair has the authority to extend the approval period in order to complete a project. **Failure to submit a final report may result in delays for future applications.**

**Please quote Project No RA/4/1/2266 all correspondence associated with this study.**

Yours sincerely

KATE KIRK  
Executive Officer  
(Human Research Ethics Committee)

App. Proj



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Our Ref. RA/4/1/1469

23 June 2006

Dr J Ng  
School of Population Health - M431  
UWA

**HUMAN RESEARCH ETHICS COMMITTEE**

**Project: Study of blindness In WA**

Please be advised that ethical approval of the above project has been granted by the Human Research Ethics Committee.

The Committee is bound by NHMRC Guidelines to monitor the progress of all approved projects until completion to ensure that they continue to conform to approved ethical standards.

The committee requires that all Chief Investigators report **Immediately** anything that might affect or impact upon ethical approval of the project, including adverse events affecting subjects.

Approval should be sought in writing **in advance** for any amendments to the original application. You are also required as a condition of this approval to inform the Committee if for any reason the research project is discontinued before the expected date of completion.

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**Please note that approval has been granted for a period of four years. Initial approval is for a period of one year, and, thereafter for future periods of one year at a time subject to the receipt of satisfactory annual reports.** At the end of the four-year period you will be required to complete a new "*Application to Undertake Research Involving Human Subjects*" should you wish to continue with your research. However, in special circumstances, the Chair has the authority to extend the approval period in order to complete a project.

**Please quote Project No RA/4/1/1469 all correspondence associated with this study.**

Yours sincerely

KATE KIRK  
Executive Officer  
(Human Research Ethics Committee)

App. Proj



Government of **Western Australia**  
Department of **Health**

**HUMAN RESEARCH ETHICS COMMITTEE (DOHWA HREC) AHEC EC00422**

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Prof James Semmens  
Director, Centre for Population Health Research  
Curtin Health Innovation Research Institute  
Curtin University  
GPO Box U1987  
PERTH WA 6845

**Project #2010/37**

**Epidemiology of Blinding Eye Disease Study (EBEDS): Identifying the Healthcare Burden of Blindness in Western Australia**

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<b>Date of commencement:</b>	01/01/2010	
<b>Date of completion:</b>	31/12/2011	
<b>Research Team:</b>	Prof James Semmens Adj/Prof Nigel Morlet Aqif Mukhtar	Prof Bill Morgan Dr Katrina Spillsbury Julie Crewe
<b>DOH data required:</b>	Yes	
<b>Data linkage required:</b>	Yes	
<b>Datasets to be accessed:</b>	WA Cancer Registry; Mortality; Hospital Morbidity;	Mental Health Information System; Emergency Department Data; Electoral Roll
<b>Ethics approval validity:</b>	valid to: 08/09/2014	

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**CERTIFICATE OF APPROVAL - AMENDMENT**

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**Date of request:** 11/02/2011  
**Date of next annual progress report:** 08/09/2011  
**Date of approval:** 09/03/2011  
**Requested Change/s:** Extend look back period to July 1999 to provide up to 5 years health service data  
**Additional information and/or request:** Nil

---

A/Prof Judith Allen  
Chair  
Department of Health WA Human Research Ethics Committee

18 March 2011

# Appendix 2: Diabetic retinopathy screening and management survey questionnaires

## Diabetic Retinopathy National Questionnaire *Ophthalmologists*

1. How many years have you been practicing ophthalmology? (exclude training years): \_\_\_\_\_
2. Where did you complete your medical training?
 

☐ Australia
 ☐ New Zealand
 ☐ United Kingdom
 ☐ Other (specify): \_\_\_\_\_
3. In which State/Territory do you currently practice?
 

☐ NSW
 ☐ VIC
 ☐ ACT
 ☐ TAS
 ☐ QLD
 ☐ WA
 ☐ NT
4. For each location where you practice please indicate whether it is a rural/metropolitan practice and estimate the monthly number of patients you would normally see (include public hospital outpatient clinics):
 

Practice 1: ☐ Rural ☐ Metropolitan Number of Patients per month: \_\_\_\_\_

Practice 2: ☐ Rural ☐ Metropolitan Number of Patients per month: \_\_\_\_\_

Practice 3: ☐ Rural ☐ Metropolitan Number of Patients per month: \_\_\_\_\_
5. If you have a sub-specialty interest, is it:
 

☐ Vitreo-retinal surgery
 ☐ Medical retina
 ☐ Anterior segment
 ☐ Oculo-plastics
 ☐ Other sub-specialty
6. Please select which of the following describes your current practice most accurately:
 

☐ General ophthalmologist
 ☐ Minor sub-specialty interest
 ☐ Mostly sub-specialist
 ☐ Exclusively sub-specialist
7. Please estimate the percentage of your patients who have diabetes:
 

☐ Less than 1%
 ☐ 1-5%
 ☐ 5-10%
 ☐ 10-15%
 ☐ More than 15%
8. Please estimate how many times you have either ordered or performed the following procedures and tests for patients with diabetes in the last 12 months:
 

	Less than once a month	Up to 10 per month	10 to 20 per month	20 to 30 per month	More than 30 per month
Focal or Grid Macular Photocoagulation:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pan Retinal Photocoagulation:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Optical Coherence Tomography:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Retinal Photography:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. How would you rate your confidence in clinically determining either the presence or absence of the following signs?
 

	Always unsure	Often unsure	Often confident	Always confident
New Vessels away from the disc:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Moderate retinal thickening near the macula:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Consider how you would normally manage patients who have diabetes:
 

	Never	Every 2 years	Yearly	6 monthly	More than 6 monthly
How often do you ask about sugar control?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How often do you ask about blood pressure?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How often do you ask about blood cholesterol?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How often do you review smoking status?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How often do you advise about the importance of the above factors in delaying complications?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Do you send recall notices to your patients who have diabetes to remind them to return for examination?
 

☐ No
 ☐ Yes
12. When you advise your patients with diabetes to return to your clinic for retinopathy examination, what percentage would return within a reasonable time of the suggested follow up visit?
 

☐ less than 30%
 ☐ 30 to 50%
 ☐ 50-70%
 ☐ 70-90%
 ☐ 90 to 100%

PLEASE TURN OVER PAGE



### Diabetic Retinopathy National Questionnaire *Ophthalmologists*

**19. How strong is your desire to play more of a role in community screening for diabetic retinopathy?**

- ☐ No Desire      ☐ Small Desire      ☐ Moderate Desire      ☐ Strong Desire

**20. How strong is your need to learn more about diagnosis and/or management of diabetic retinopathy?**

- ☐ No Need      ☐ Small Need      ☐ Moderate Need      ☐ Strong Need

**21. Consider the following patients with poorly controlled diabetes and normal vision. You are confident that they do not have any macula oedema. How often would you order a fluorescein angiogram at their initial presentation if you detected the following signs:**

	Almost never	Sometimes	Often	Almost always	I'd refer elsewhere
No retinopathy:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Mild Non-Proliferative Retinopathy:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Severe Non-proliferative Retinopathy:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**22. You see a patient with diabetes. They have a cataract that requires surgery and also have clinically significant macular oedema. The cataract will make it difficult but not impossible to perform laser therapy to the macula. Which would you normally aim to do? (tick one option)**

- ☐ Refer Elsewhere      ☐ Delay macular laser therapy until after cataract surgery      ☐ Delay cataract surgery until after macular laser therapy

**23. You see a patient with diabetes who requires Pan-Retinal Photocoagulation (PRP) for early proliferative diabetic retinopathy and Focal Macular Photocoagulation for clinically significant macular oedema. How would you normally manage them? (tick one option)**

- ☐ Refer Elsewhere      ☐ Perform PRP and wait until a later date to perform macular photocoagulation      ☐ Perform macular photocoagulation and wait until a later date to perform PRP      ☐ Perform both procedures together

**24. The following patients have no signs of retinopathy and no ophthalmic problems at your baseline examination. Assume that they are compliant with your follow up instructions. How would you manage them?**

	Refer elsewhere for regular eye screening	Advise regular eye screening in about 5 yrs	Review in 2 yrs	Review in 1yr	Review in 6 months or less
A 7yr old child recently diagnosed with diabetes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
An 18 yr old recently diagnosed with diabetes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A 60 yr old recently diagnosed with <u>very mild</u> diabetes ("a touch of sugar") well controlled by dietary means alone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A 60 yr old recently diagnosed with diabetes and commenced on oral medications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A 60 yr old with a 10 yr history of diabetes, achieving good glycaemic control with oral medications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A 60 yr old with a 10 yr history of diabetes, achieving good glycaemic control but requiring insulin	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A 60 yr old with a 10yr history of diabetes, requiring insulin but still poorly controlled	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**25. The following patients are all 60 years old and have a 10 year history of diabetes, well controlled with oral medications. You have detected the following signs and are confident that there is no macular oedema and no other signs or problems. Assume that vision is normal, that there are no other eye problems and that the patients are compliant. How would you normally manage them?**

	Refer elsewhere	Review in 2 yrs	Review in 1 yr	Review in 6 months	Review in 3 months, no angiogram	Angiogram ± Laser
Occasional microaneurysms located outside the macula	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Numerous, widespread microaneurysms and retinal haemorrhages, all located outside the macula	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Numerous, widespread microaneurysms and retinal haemorrhages with venous bleeding in 2 quadrants, all located outside the macula	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

\*\*\* END OF SURVEY – THANK YOU FOR YOUR CONTRIBUTION \*\*\*

### Diabetic Retinopathy National Questionnaire *Optometrists*

1. How many years have you been practicing optometry?(exclude training years): \_\_\_\_\_
2. In which State/Territory do you currently practice?  
☐ NSW    ☐ VIC    ☐ ACT    ☐ TAS    ☐ QLD    ☐ WA    ☐ NT
3. Where did you complete your medical training?  
☐ Australia    ☐ New Zealand    ☐ United Kingdom    ☐ Other (specify): \_\_\_\_\_
4. For each location where you practice please indicate whether it's rural/metropolitan and estimate the monthly number of patients you would normally see (include public hospital outpatient clinics):  
 Practice 1:    ☐ Rural    ☐ Metropolitan    Number of Patients per month: \_\_\_\_\_  
 Practice 2:    ☐ Rural    ☐ Metropolitan    Number of Patients per month: \_\_\_\_\_  
 Practice 3:    ☐ Rural    ☐ Metropolitan    Number of Patients per month: \_\_\_\_\_
5. Regarding the NHMRC Guidelines for the Management of Diabetic Retinopathy published in 1997:  
 Do you receive a copy?    ☐ Yes    ☐ No (skip to question 6)  
 Have you read them?    ☐ Not at all    ☐ Partially    ☐ Once entirely    ☐ Several times
6. Please estimate the percentage of your patients who are diabetic:  
☐ Less than 1%    ☐ 1-5%    ☐ 5-10%    ☐ 10-15%    ☐ More than 15%
7. Consider new patients over 40 years old. How often do you ask specifically whether or not they have been diagnosed with diabetes?  
☐ Almost never    ☐ Sometimes    ☐ About half the time    ☐ Often    ☐ Almost always
8. Consider new patients over 40 years old who do not have a narrow angle or a history that is specifically suggestive of diabetes, glaucoma or a retinal problem. How often would you perform dilated ophthalmoscopy on them?  
☐ Almost never    ☐ Sometimes    ☐ About half the time    ☐ Often    ☐ Almost always
9. Among new patients who you know have diabetes, how often do you perform dilated ophthalmoscopy? (assume they are not receiving dilated exams elsewhere)  
☐ Almost never    ☐ Sometimes    ☐ About half the time    ☐ Often    ☐ Almost always
10. How would you rate the following as barriers to you performing dilated ophthalmoscopy on patients with diabetes?  

	Not a barrier	Minor barrier	Moderate barrier	Major barrier
Time consuming to dilate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patients don't want to be dilated	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Worried you will precipitate angle closure glaucoma	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patients are unprepared eg need to drive after	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not confident in detecting changes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Unsure what to do if changes are detected	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of dilating drops in the practice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of ophthalmoscope in your practice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. How often do you use the following instrument when you examine patients with diabetes?  

	Almost never	Sometimes	Half the time	Often	Almost always
Direct ophthalmoscope:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Monocular Indirect Ophthalmoscope:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Binocular Indirect Ophthalmoscope:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Slit lamp fundus viewing lens:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Retinal camera:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. How would you rate your confidence in clinically determining either the presence or absence of the following signs?  

	Always unsure	Often unsure	Often confident	Always confident
Microaneurysms:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hard Exudates:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
New Vessels away from the disc:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Moderate retinal thickening near the macula:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

PLEASE TURN OVER PAGE

### Diabetic Retinopathy National Questionnaire *Optometrists*

**13. Consider how you would normally manage patients who have diabetes:**

	Never	Every 2 years	Yearly	6 monthly	More than 6 monthly
How often do you ask about blood sugar control?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How often do you ask about blood pressure control?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How often do you ask about blood cholesterol control?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How often do you review smoking status?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How often do you advise about the importance of the above factors in delaying complications?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**14. Do you send recall notices to your patients who have diabetes to remind them to return for examination?**

☐ No ☐ Yes

**15. When you advise you patients with diabetes to return to your clinic for retinopathy examination, what percentage would return within a reasonable time of the suggested follow up visit?**

☐ less than 30% ☐ 30 - 50% ☐ 50 - 70% ☐ 70 - 90% ☐ 90 - 100%

**18. What do you think is the rate of compliance with your instructions for patients with diabetes to visit ophthalmologists?**

☐ less than 30% ☐ 30 - 50% ☐ 50 - 70% ☐ 70 - 90% ☐ 90 - 100%

**19. How strong is your desire to play more of a role in community screening for retinopathy among people with diabetes? (under current Medicare arrangements)**

☐ No Desire ☐ Small Desire ☐ Moderate Desire ☐ Strong Desire

**20. How strong is your need to learn more about diagnosis and/or management of retinopathy among people with diabetes?**

☐ No Need ☐ Small Need ☐ Moderate Need ☐ Strong Need

**21. The following patients have no signs of retinopathy and no ophthalmic problems at your baseline examination. Assume that they are compliant with your follow up instructions. How would you manage them?**

	Refer to an ophthalmologist	Advise regular dilated eye exams in about 5 yrs	Dilate in 2 yrs	Dilate in 1yr	Dilate in 6 months or less
A 7yr old child recently diagnosed with diabetes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
An 18 yr old recently diagnosed with diabetes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A 60 yr old recently diagnosed with <u>very mild</u> diabetes ("a touch of sugar") well controlled by dietary means alone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A 60 yr old recently diagnosed with diabetes and commenced on oral medications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A 60 yr old with a 10 yr history of diabetes, achieving good glycaemic control with oral medications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A 60 yr old with a 10 yr history of diabetes, achieving good glycaemic control but requiring insulin	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A 60 yr old with a 10yr history of diabetes, requiring insulin but still poorly controlled	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**22. The following patients are all 60 years old and have a 10 year history of diabetes, well controlled with oral medications. You have detected the following signs and are confident that there is no macular oedema and no other signs or problems. Assume that vision is normal, that there are no other eye problems and that the patients are compliant. How would you normally manage them?**

	Refer to an ophthalmologist	Review in 2 yrs	Review in 1 yr	Review in 6 months	Review in 3 months
Occasional microaneurysms located peripherally:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Macular oedema that is not clinically significant:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Peripheral microaneurysms plus occasional retinal haemorrhages:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Extensive microaneurysms and retinal haemorrhages and occasional cotton wool spots, all located peripherally:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Proliferative retinopathy:	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

\*\*\*END OF SURVEY – THANK YOU FOR YOUR CONTRIBUTION\*\*\*

## Diabetic Retinopathy National Questionnaire *General Practitioners*

1. How many years have you been practicing medicine? (exclude training years): \_\_\_\_\_ yrs

2. Where did you complete your medical training?

☐ Australia      ☐ New Zealand      ☐ United Kingdom      ☐ Other (specify): \_\_\_\_\_

3. In which State/Territory do you currently practice?

☐ NSW      ☐ VIC      ☐ ACT      ☐ QLD      ☐ WA      ☐ NT      ☐ TAS

4. Are you in a rural/remote or metropolitan practice?    ☐ Rural/Remote      ☐ Metropolitan

5. Regarding guidelines for managing diabetic retinopathy:

Did you receive a copy of the 1997 NHMRC Guidelines for the Management of Diabetic Retinopathy?

☐ Yes      ☐ No (skip to question 5)

Have you read them?    ☐ Not at all      ☐ Partially      ☐ Once entirely      ☐ Several times

Do you refer to other published guidelines when managing your diabetic patients?    ☐ No    ☐ Yes (specify): \_\_\_\_\_

6. Consider how you would normally manage patients who have diabetes:

	Never	Every 2 years	Yearly	6 monthly	More than 6 monthly
How often do you measure glycosylated haemoglobin?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How often do you measure blood pressure?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How often do you measure blood cholesterol?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How often do you review smoking status?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
How often do you advise about the role of the above factors in developing complications?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7. What proportion of your diabetic patients would you examine for diabetic retinopathy?

☐ None (skip to question 10)    ☐ Less than half    ☐ About half    ☐ More than half    ☐ All

8. On average how often do you examine your diabetic patients for retinopathy?

☐ More than annually    ☐ Annually    ☐ Every 2 years    ☐ Every 3-5 years    ☐ Less than 5 yearly

9. When you examine patients for diabetic retinopathy do you:

	Never	Rarely	Sometimes	Usually	Always
Measure visual acuity?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Perform fundoscopy without dilating eye drops?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Perform fundoscopy with dilating eye drops?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

10. How often do you feel confident in being able to detect clinical signs of diabetic retinopathy?

☐ Almost never    ☐ Sometimes    ☐ About half the time    ☐ Often    ☐ Almost always

11. How would you rate the following as barriers to you performing dilated ophthalmoscopy on patients with diabetes?

	Not a barrier	Minor barrier	Moderate barrier	Major barrier
Time consuming to dilate	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patients don't want to be dilated	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Worried you will precipitate angle closure glaucoma	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Patients are unprepared eg need to drive after	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Not confident in detecting changes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Unsure what to do if changes are detected	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of dilating drops in the practice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lack of ophthalmoscope in your practice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

12. How often would you refer your diabetic patients to the following eye care professionals?

	6 monthly	Annually	Every 2 <sup>nd</sup> year	Every 5 years	Only if visual symptoms present	Never
Ophthalmologist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Optometrist	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

PLEASE TURN OVER PAGE

### Diabetic Retinopathy National Questionnaire *General Practitioners*

**13. What proportion of your diabetic patients do you think are compliant with your instructions to visit an ophthalmologist?**

- ☐ less than 30%      ☐ 30 to 50%      ☐ 50-70%      ☐ 70-90%      ☐ 90 to 100%

**14. Consider the following scenarios that relate to a 60 year old patient with a 10 year history of type 2 diabetes mellitus well controlled on oral medication. Assume that vision is normal, there are no other eye problems and the patient is 100% compliant with your management. How would you manage them given you have found the following signs?:**

	Refer to an ophthalmologist within a week	Refer to an ophthalmologist within a month	Refer to an ophthalmologist within a year	Do not refer, review later
Occasional microaneurysms with normal vision	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hard exudates near the macula with normal visual acuity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Peripheral microaneurysms plus occasional peripheral retinal haemorrhages	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Extensive microaneurysms, retinal haemorrhages and occasional cotton wool spots, all located peripherally	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
New vessels covering an area of about half that of the optic disc and normal visual acuity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**15. The following patients have no signs of retinopathy and no ophthalmic problems at your baseline examination. Assume that they are compliant with your follow up instructions. How would you manage them?**

	Refer elsewhere for regular eye screening	Advise regular eye screening in about 5 yrs	Review in 2 yrs	Review in 1yr	Review in 6 months or less
A 7yr old child recently diagnosed with diabetes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
An 18 yr old recently diagnosed with diabetes	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A 60 yr old recently diagnosed with <u>very mild</u> diabetes ("a touch of sugar") well controlled by dietary means alone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A 60 yr old recently diagnosed with diabetes and commenced on oral medications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A 60 yr old with a 10 yr history of diabetes, achieving good glycaemic control with oral medications	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A 60 yr old with a 10 yr history of diabetes, achieving good glycaemic control but requiring insulin	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
A 60 yr old with a 10yr history of diabetes, requiring insulin but still poorly controlled	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

\*\*\*END OF SURVEY – THANK YOU FOR YOUR CONTRIBUTION \*\*\*

## **Appendix 3: The electronic cataract audit and reporting tool**

## Improving cataract surgery outcomes: The implementation of a State-wide Cataract Surgery Register

# Final Report

### Investigators:

Dr David B Preen  
Professor James B Semmens  
A/Professor Nigel Morlet  
Dr Antony Clark  
Dr Jonathon Q Ng

**Prepared by:** Mrs Patricia Barrett & Dr Antony Clark

### Overview

Cataract surgery is the most commonly performed operation in Australia.<sup>1</sup> Whilst complications are uncommon, they can lead to worse visual outcomes and even blindness. Over the next decade the number of cataract procedures performed each year, along with the number of complications, is expected to double as a result of our ageing population.

Through previous studies into cataract complications by the Centre for Population Health Research (CPHR) group the need for a prospective and more detailed method of collecting data relating to cataract complications was highlighted. Hospital administrative databases do not record basic operative information, and even chart review is not sufficient since the level of detail recorded on operation sheets is extremely variable and clinically important information is often not recorded. Without this information comment upon the impact of operative factors on the outcomes of cataract surgery cannot be reliably made.

We aim to reduce the risk of adverse outcomes of cataract surgery by providing a more robust evidence base to identify clinical factors that may be associated with adverse outcomes. Operative factors such as intra-ocular lens type, incision location and use of antibiotics are not routinely collected for analysis, yet are very important because they can affect the risk of adverse outcomes. Timely availability of this information will improve our ability to provide ophthalmologists with the appropriate evidence to ensure best quality clinical practice and reduce the risk of iatrogenic vision loss and blindness.

The implementation of the Electronic Cataract Auditing Tool (eCAT) database is designed to overcome the deficiencies found with our current data sets by requesting basic operative information from every cataract operation performed in WA. This will provide the information required for assessment of operative factors on cataract surgery outcomes in a standardised format that is readily accessible, up-to-date and validated.

The specific objectives proposed for this project include:

**Objective 1:** Implement a web-based registry of cataract surgery in a cross-section of WA hospitals

**Objective 2:** Use the cataract surgery registry to collect prospective data on cataract surgery procedures performed in WA

**Objective 3:** Determine the usefulness of the registry in assessing selected outcomes of cataract surgery in a cross-section of WA hospitals with a pilot study

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<sup>1</sup> Australian Institute of Health and Welfare. 2005. Vision Problems Among Older Australians. Bulletin no.27 AIHW cat. No. Aus 60. Canberra: AIHW.

Project Activities

Promotion

Promotion of the developed eCAT System to the local ophthalmology community was a key initial step towards engendering widespread support for its introduction across WA health sites. We have extensively promoted the eCAT system to all WA ophthalmologists and other ophthalmic health care professionals within the State during the course of the last 12 months. The System was also promoted and demonstrated at several clinical conferences/meetings, including:

- 1. The WA RANZCO Branch Meeting, February 2009, Margaret River
- 2. Ophthalmology Board Meeting, St John of God Hospital, March 2009, Subiaco
- 3. Southwest Eye Surgeons CME Meeting, April 2009 , Bussetton
- 4. Ophthalmology Clinico-pathology Meeting, Royal Perth Hospital, July 2009, Perth

These presentations ([Appendix 1](#)) provided a broad overview of how the eCAT system operates and its potential advantages in terms of supporting personal monitoring, clinical audit and scientific research. They were well received and very successful in generating significant interest and enthusiasm among ophthalmologists towards the eCAT system.

Implementation

Proposed Institutions	Implemented	Notes
<b>Tertiary Hospitals</b>		
Royal Perth Hospital	✓	Implemented but beta testing in progress.
Sir Charles Gairdner	✓	
Fremantle Hospital and Health Service	✓	
<b>Peripheral Hospitals</b>		
Osborne Park Hospital	✗	Awaiting final changes to be made in response to beta testing at the Tertiary hospitals. Anticipate implementation within 3 months.
Swan Districts Hospital	✗	
Bentley Hospital	✗	
<b>Private Hospitals</b>		
The Eye Surgery Foundation (ESF)	✓	Beta testing commenced.
Lions Eye Institute	✗	Implementation to commence when ESF beta testing successfully completed.
St John of God Subiaco	✗	
St John of God Bunbury	✗	

Beta testing of the eCAT web-based cataract surgery software system by clinicians is well underway in the major metropolitan tertiary hospitals in Perth (Royal Perth Hospital, Sir Charles Gairdner Hospital and Fremantle Hospital & Health Services). Beta testing is also underway at the WA Eye Surgery Foundation (ESF) and we are currently addressing important network and IT infrastructure compatibility issues associated with its installation at this institution. It is expected that implementation at the ESF will be completed by October 31<sup>st</sup> 2009, and the processes employed at the ESF will form the framework for implementation of the eCAT system into the other private hospitals (Lions Eye Institute, and St John of God Subiaco and Bunbury).

The initial implementation and beta testing of the eCAT system into Tertiary hospital sites generated a great deal of feedback regarding system network issues, areas for improvement and requested additions. We felt it was important to address these changes early on within the tertiary setting prior to further roll-out. This has involved an unanticipated increased commitment in time and resources, which we felt to be essential if we are to ensure widespread user acceptability of the system across the State as it is rolled-out.

Therefore, implementation of the eCAT system into the other public hospital sites (Osborne Park Hospital, Swan Districts Hospital, and Bentley Hospital) has been delayed until the changes required have been fully implemented and tested in the Tertiary setting. It is expected that implementation through these institutions will be on an accelerated trajectory as impediments are rectified, and we anticipate completion by January 2010. Similarly, we have elected to implement the system in only one private health site - The Eye Surgery Foundation (ESF) - and have delayed implementation in the other proposed private hospitals until the system is fully tested and fully operational in the public hospitals and ESF. The Lions Eye Institute has asked to delay installation and beta testing at their site as they are currently upgrading their data base management tools, and it is not efficient to undertake the programming to allow the old version to communicate with the eCAT system, then to have to make alterations to accommodate the new system.

Installation at the two St. John of God hospitals in the pilot group, Perth and Bunbury, will also need additional programming to allow the eCAT system to interface with their database management tools. This is currently being addressed as beta testing and evaluation continues at the other sites.



## Feedback

We have been very proactive in our desire to receive feedback on the eCAT System from clinicians and other senior clinical and administrative hospital staff who have been involved with beta testing of the system at each of the current test sites. The feedback we have sought so far has been from face-to-face contact and surrounds several areas including:

1. Views on mandatory recording requirements i.e. establishing a universally agreed minimum data set.
2. Individual reporting requirements for each health site in terms of requirements for operation reports, medical records and discharge summaries.
3. Adequacy of the user interface and menu options.
4. Identifying hardware requirements to facilitate eCAT integration into operating theatres.
5. Identifying perceived barriers to surgeons in using the eCAT system ongoing.

We have also developed a survey tool ([Appendix 2](#)) that will be administered to all clinicians who have been using the eCAT system once it is fully implemented in the public system. The purpose of this evaluation is to:

- Provide users the opportunity to guide software development by identifying areas in which improvements may be made to maximise end-user uptake; and
- Ascertain end-user attitudes to establishing a cataract surgery clinical register in WA including perceived benefits (e.g. assistance with personal clinical audit, public health gains, greater efficiency in discharge planning process), and risks (e.g. privacy, league tables).

## Improvement

The eCAT system has undergone significant changes over the last 12 months in response to feedback from clinicians and our desire to ensure it complies with Australian National e-Health standards.<sup>2,3</sup> Areas of improvement for the eCAT System that have subsequently been addressed include:

- 1.1. An upgrade of the data entry protocol and security features to meet Australian Standard AS 5017-2006 Health Care Client Identification, Australian Standard AS 4846-2004 Health Care Provider Identification and the new National E-Health Transition Authority (NEHTA) Interoperability Framework Version 2.0 (NEHTA 0130:2007) standards for electronic data collection. These system modifications were extensive yet essential to ensure the system meets the most current security and e-health requirements at a national level.
- 1.2. A new "Maintenance" section has been built into the web-based system to allow individual institutions to easily make changes/additions various features to suit their particular context. This includes:
  - 1.1. Customisable system menus (e.g. the addition of particular intraocular lens types, or a particular type of phacoemulsification machine).
  - 1.2. Customisable perioperative medications section.
  - 1.3. Customisable operative difficulties section.
  - 1.4. Customisable operation reports for printing into the patient notes, discharge summaries and GP letters.
  - 1.5. The ability for each health site to control their own user-level access.
- 1.3 The identification and resolution of system "bugs" ([Appendix 3](#))
- 1.4 Changes to the mandatory reporting requirements and 'templated' items to improve efficiency of data entry and decrease the time required to complete the operation report. This represented a significant issue raised by participating surgeons, and was required to be fully addressed to ensure uptake and compliance of the System by clinicians.

## Documentation

We have been working hard to develop a comprehensive 'eCAT User Reference Manual' to assist clinicians at all health sites manage the eCAT system independently into the future ([Appendix 4](#)). Additionally, we are working towards developing an 'eCAT Maintenance Manual' ([Appendix 4](#)) to outline the protocols that should be followed by all participating health sites using the eCAT system. Due to the multi-site nature of the proposed eCAT system and its high degree of customisation to suit individual health sites and clinicians, it is essential that a common protocol for data entry and system alterations be developed so as to ensure standardisation of all data in the system across the different health sites.

<sup>2</sup> Standards Australia e-health [online], Available at: <http://www.e-healthstandards.org.au> [Accessed 10 September 2009]

<sup>3</sup> National E-Health Transition Authority [online], Available at: <http://www.nehta.gov.au> [Accessed 10 September 2009]

### Project Difficulties

As outlined in previous project progress reports, a number of difficulties have been experienced in the conduct of this pilot project to date that have led to significant delays in achieving our project objectives. These include:

#### Staffing

Due to the competitive WA employment market early in the project, there was difficulty with the immediate employment of an appropriately skilled candidate for the position of project coordinator. This led to a delay of a number of months in commencement of the project and in implementation of the eCAT system in the pilot hospitals. Subsequently, the project experienced a change in personnel as the original project coordinator employed for this project resigned from the position due to health reasons in May 2009. In addition to the delay with recruitment, substantial time was required for training of the new project coordinator.

#### IT Issues/system modifications

As outlined above, significant modifications were required to be made to the data entry protocols for the eCAT system to ensure compatibility with recently released NEHTA standards. The move towards a national eHealth standards was unexpected at the time of project commencement, but essential for the future longevity of the eCAT System. Additionally, and as a result of feedback from clinical end-users of the System, significant modifications to the eCAT form were required to: a) increase user acceptability; and b) improve deficiencies identified in the process of beta testing the system. Therefore, we have been highly reliant upon hospital IT services in order to make the changes required and allow beta testing to move forward. These services were not budgeted for in the project and our reliance on the goodwill of our IT services to make these changes has resulted in significant additional delays.

When we began looking at installation at the private sites, initially the Eye Surgery Foundation (ESF), we encountered difficulties in accessing the theatre list from the private hospital due to the different database management tools used at the private sites. For example, the eCAT system used SQL Server as the database management tool, and the ESF uses MySQL. The eCAT system is accessed via the theatre list, which is stored on the hospital site's system. Therefore the eCAT system needs to be able to interrogate the private site's database in order to access the patient names on the theatre list. This meant extra planning and computer programming time to make this possible at the private sites. As each site uses a different database management tool, the programming needs to be re-worked for each private site.

### Future Progress

The eCAT system is currently being used successfully in all of Perth's Tertiary hospitals to record cataract surgery data and generate a comprehensive, and clinically useful cataract surgery post-operative report. We envision further roll-out of the eCAT system to other public hospitals will be a relatively smooth process since the networking/IT infrastructure required for eCAT at these sites is already in place. Furthermore, the clinicians who operate in these hospitals also operate in the tertiary setting and so will already be familiar with eCAT. Implementation within these institutions is expected to be completed by January 2010.

Formal consultation has been held with the Ophthalmology Head of Department at each of the proposed private hospital sites (SJOG Bunbury and Subiaco, LEI) and all institutions have agreed to implement the eCAT system. Implementation of the eCAT system in Perth's major private hospitals will require additional support from each facility's IT service since the networking infrastructure at each site is different. However, using the lessons gained from implementing the system in the ESF we are better able to anticipate possible difficulties, and it is expected that implementation within these private hospitals will be achieved by June 2010.

As yet, we have not yet needed to use any of the hardware budget as the public hospitals and the Eye Surgery Foundation have their own printers that we were able to access. It is anticipated that when the system is implemented at the smaller public hospitals and private sites these monies will be needed to purchase additional hardware.

# eCAT

## Electronic Cataract Auditing Tool

Nigel Morlet • Jonathon Q Ng • Antony Clark



### *Appendix 1*

## *Powerpoint Presentation*

# What information is recorded?

- Comprehensive list of mandatory and optional items
- Examples:
  - Anaesthesia
  - IOL implant
  - Blades
  - Medications
  - Post-operative orders



## Purpose

- Advanced browser-based software system
- Recording standardise information
- Produces operation report, discharge summary and postoperative orders
- Personal auditing



# Searching for patient

- Patients are linked into the system through hospital theatre lists
- Patients can be searched for by:
  - Patient identifiers
  - Theatre list by date

Department of Health eCAT Ophthalmology - Cataract Surgery Audit and Reporting - ver 1.0.0 Delivering a Healthy WA

Friday, 27 Feb 2009 - RE3452 - Kyle Van-Minnen - Sir Charles Gardiner Hospital WARNING: This page will automatically close in 594 seconds

CPI Search | Theatre List | Procedures | Templates | Maintenance | Help | Log Off

Identifier  \* at least 8 characters required for identifier searches

Type TOPAS - UMRN

OR (entered identifiers override names, DOB, etc.)

Family name  \* at least 2 characters required for name searches

Given name  \* at least 2 characters required for name searches

Gender

DOB

Year of Birth  to  (range)

UMR	Patient	DOB	Gender	Status
A0000001	SMITH, ANGELA	01 Jan 1950	Female	
A0000006	SMITH, ANTHONY	01 Jan 1950	Male	

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Friday, 27 Feb 2009 - RE3452 - Kyle Van-Minnen - Sir Charles Gardiner Hospital WARNING: This page will automatically close in 660 seconds

CPI Search | Theatre List | Procedures | Templates | Maintenance | Help | Log Off

Date of Surgery  27/02/2009

UMR	Patient	DOB	Gender	Consultant	Status
A0000001	SMITH, ANGELA	01 Jan 1950	Female	MORLET, N.	
A0000006	SMITH, ANTHONY	01 Jan 1950	Male	MORLET, N.	
A0000007	SMITH, BELINDA	01 Jan 1950	Female	MORLET, N.	
A0000015	SMITH, BRITTANY	01 Jan 1950	Female	MORLET, N.	
A0000028	SMITH, DANIEL	01 Jan 1950	Male	MORLET, N.	
A0000024	SMITH, DAVID	01 Jan 1950	Male	MORLET, N.	
A0000013	SMITH, DAVID	01 Jan 1950	Female	MORLET, N.	
A0000003	SMITH, DOROTHY	01 Jan 1950	Female	MORLET, N.	
A0000002	SMITH, DOROTHY	01 Jan 1950	Female	MORLET, N.	
A0000008	SMITH, GORDON	01 Jan 1950	Male	MORLET, N.	
A0000025	SMITH, JASON	01 Jan 1950	Male	MORLET, N.	
A0000012	SMITH, JILLIAN	01 Jan 1950	Female	MORLET, N.	
A0000029	SMITH, JOHANNES	01 Jan 1950	Male	MORLET, N.	
A0000017	SMITH, JOHN	01 Jan 1950	Male	MORLET, N.	



# How to use the form

- A security-enabled web-based portal
- Logon to the system using password

GOVERNMENT OF WESTERN AUSTRALIA Department of Health Delivering a Healthy WA

Friday, 27 Feb 2009

Healthy Workforce • Healthy Hospitals • Healthy Partnerships • Healthy Communities • Healthy Resources • Healthy Leadership

eCAT Ophthalmology - Cataract Surgery Audit and Reporting : ver 1.0.0

**Secure Login**

Please enter your network Username and Password to gain access to this system

Site

Username

Password

Your access to this system is governed by an acceptable use standard, which formed part of your request for access. The full standard is available upon request from Health ICTS.

If you require assistance please contact your helpdesk



**(mandatory items are in bold)**

- Items from template will be automatically filled on form

**eCAT**  
Ophthalmology - Cataract Surgery Audit and Reporting - ver 1.0.0

Wednesday, 04 Mar 2009 - HE94642 - Kylie Van-Ilmnen - Sir Charles Gardiner Hospital

CPI Search | Theatre List | Procedures | Templates | Maintenance |

WARNING: This page will automatically close in 844 seconds  
| Help | Log Off

---

Patient:	A0000020 - EWEN, JEFFREY	Consultant:	
D.O.B:	16 Apr 1961	Location:	
Gender:	Male	Admission:	
Address:	1 MAJIN STREET, PERTH, 5000	Case Number:	0

---

### Edit Procedure Details

* Surgeon	Morlet Nigel	Level	Consultant
Assistant 1		Level	
Assistant 2		Level	
Case Completion	Entirely by surgeon		

\* Eye    Right ☒    Left ☐

\* Procedure    Phacoemulsification

\* Procedure Date    4/03/2009

\* Start    0 | 2 | : 4 | 4   

\* Stop    0 | 3 | : 0 | 9       Op Time    0 | 2 | : 5 minutes

---

### Patient History

Cataract Type    Age Related

Biometry

AXL	3	0	:	0	0	mm	
K1	3	2	:	0	0	D	
K2	4	1	:	0	0	D	

x    0 | 2 | : 0   

x    1 | 1 | : 0   

Anticipated Difficulty    Routine

# Using Template

- Utilise customised template to reduce data entry
- Up to 57% of forms information can be pre-entered on template
- Multiple templates can be made

[illegible]

# Viewing procedure

- Once a patients operation has been entered:
  - Can view historical list of procedures performed
  - View PDF of procedure reports

Department of Health eCAT Ophthalmology - Cataract Surgery Audit and Reporting ver 1.0.0 Delivering a Healthy WA

Friday, 27 Feb 2009 - HE94842 - Kylie Van-Minnen - Sir Charles Gairdner Hospital WARNING: This page will automatically close in 888 seconds

CPI Search | Theatre List | Procedures | Templates | Maintenance | Help | Log Off

Patient: A0000001 - SMITH, ANGELA Consultant:  
 DOB: 01 Jan 1950 Location:  
 Gender: Female Admission:  
 Address: Case Number: 0

**Recorded Procedures**

Procedure	Date	Site	Surgeon	Eye	Actions
Phacoemulsification	27 Feb 2009	RP	Kylie, Van Minnen	R	

[Add New \( Without Template \)](#)

**Default Templates**

Procedure	Default Template Description	Actions
Phacoemulsification	Phaco 1	

[Add New Default Template](#)

**Operation Details**

\* Anaesthesia ☐ General ☒ Subconjunctival ☐ Subtenons  
☐ Retrobulbar ☐ Topical  
☐ Penitular ☐ IV Sedation

Anaesthesia by Surgeon: Normal healthy patient

Keratome: Steel Blade Size 1 2.00 mm 2 2.00 mm 3 . mm  
 Port: Steel 15°  
 Other Blade: . mm

Ports:

\* Wound Approach: Corneal Wound Construction: 1 Plane

\* Wound Position: 180° 0°

AC maintained by ☒ Viscoelastic ☐ Air  
☐ BSS ☐ AC Maintainer

\* Viscoelastic 1 Healon 2  
 Capsulotomy: Healon 5 (reason) following Capsulotomy  
 Capsulorhexis: (approx diameter) 3.0 mm  
 Machine: Bausch and Lomb Millennium  
 Phaco Mode: Continuous  
 Phaco Time: 0 1 2 0 min:sec Power: 0 2 0 %  
 \* or CDE  
 \* Final Wound Size: 1.5 0 mm (usually max blade size ± 0.2 mm)  
 \* IOL Implant: Alcon MC50BD \* IOL Power: 1 2 . 0 0  
 IOL Introduction: Injected IOL Position: Bag  
 \* Post Capsule Intact: Yes \* Vitreous Prolapse: Yes  
 \* Suture Wound: No \* Hydrated Wound: Yes

**Operation Difficulties**

No \* If Yes, then select below

[Show Operation Difficulties](#)

**Other Procedures**

[Show Other Procedures](#)

**Medications**

Pre-op: [Show Pre-op Medications](#)

Intra-op: [Show Intra-op Medications](#)

Immediate Post-op: [Show Immediate Post-op Medications](#)


Discharge: [Show Discharge Medications](#)

**Postoperative Orders**

Discharge: After Review  
 Follow-up (where): Rooms (when): Next Working Day  
 Orders: [Show Other Post-op Orders](#)



# Procedure reports

 Ophthalmology Procedure Report  
Printed by 3 - Van-Minnen, Kylie  
on 27 Feb 2009

enquiries ph (08) 9346 3333  
Ref: UNMR: A0000006  
Case: 0

**Consultant Copy**

Unit

Patient: SMITH, ANTHONY  
dob: 01 Jan 1950


Specialty: Consultant

Procedure: Phacoemulsification  
Date: 27 Feb 2009  
Surgeon: Morlet Nigel - Consultant  
Eye: Right

Anaesthesia: Subconjunctival  
Wound Approach: Corneal  
Wound Position: 900  
AC maintained by: Viscoelastic  
Viscoelastic 1: Healon  
Viscoelastic 2: Viscoat ( following Capsulotomy )  
Phaco Technique: Divide and Conquer  
Final Wound Size: 1.15 mm  
IOL Implant: Alcon SA60AT  
IOL Power: 12.00  
IOL Introduction: Injected  
IOL Position: Bag  
Operation Difficulties: -  
Postop Orders: Discharge Once Ambulant  
Follow-up ( where ) Eye Clinic ( when ) Next Working Day

Kylie Van-Minnen - on behalf of  
( Consultant )

CE@000000000000-200902271223023 Page 1 of 2

 Ophthalmology Procedure Report  
Printed by 3 - Van-Minnen, Kylie  
on 27 Feb 2009

enquiries ph (08) 9346 3333  
Ref: UNMR: A0000006  
Case: 0

**Medical Records Copy**

A0000006

Patient: SMITH, ANTHONY  
dob: 01 Jan 1950

Specialty: Consultant

Procedure: Phacoemulsification  
Date: 27 Feb 2009  
Surgeon: Morlet Nigel - Consultant  
Eye: Right


Anaesthesia: Subconjunctival  
Wound Approach: Corneal  
Wound Position: 900  
AC maintained by: Viscoelastic  
Viscoelastic 1: Healon  
Viscoelastic 2: Viscoat ( following Capsulotomy )  
Phaco Technique: Divide and Conquer  
Final Wound Size: 1.15 mm  
IOL Implant: Alcon SA60AT  
IOL Power: 12.00  
IOL Introduction: Injected  
IOL Position: Bag  
Operation Difficulties: -  
Postop Orders: Discharge Once Ambulant  
Follow-up ( where ) Eye Clinic ( when ) Next Working Day

Kylie Van-Minnen - on behalf of  
( Consultant )

CE@000000000000-200902271223023 Page 1 of 2

# Procedure reports

- PDF reports generated using entered data
- Report layout and information can be customised
- Produces
  - Patient report
  - Consultant report
  - Medical records report

 Ophthalmology Procedure Report  
Printed by 3 - Van-Minnen, Kylie  
on 27 Feb 2009

enquiries ph (08) 9346 3333  
Ref: UNMR: A0000006  
Case: 0

**Patient Copy**

Patient: SMITH, ANTHONY  
dob: 01 Jan 1950

Specialty: Consultant

Procedure: Phacoemulsification  
Date: 27 Feb 2009  
Surgeon: Morlet Nigel - Consultant  
Eye: Right

Anaesthesia: Subconjunctival  
IOL Implant: Alcon SA60AT  
IOL Power: 12.00  
Postop Orders: Discharge Once Ambulant  
Follow-up ( where ) Eye Clinic ( when ) Next Working Day

Kylie Van-Minnen - on behalf of  
( Consultant )

\*\*\* End of Report \*\*\*

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CE@000000000000-200902271223023 Page 1 of 2



## *Appendix 2*

# *User Evaluation Questionnaire*

## **Use of data**

- Create standardised reports
- Extract of data can be downloaded & used in personal auditing program





## Electronic Cataract Auditing Tool (eCAT) Maintenance Log

Error Number	Date Identified	Site of Error/Change	Brief Description of Error	Date finalised
EN01	17/06/09	Procedure template	Remove K1/K2 and wound enlargement/final wound size from the mandatory items. (from previous request via email 06/04/09 from Jonathon)	17/09/2009
EN02	17/06/09	Procedure template	On all templates <b>Phaco Power</b> appears to be mandatory, but it does not have an asterix.	17/09/2009
EN03	17/06/09	Printable PDF forms	The PDF forms (discharge etc.) apply the logo for the site where the user is logged not where the operation was performed.	9/1/2009
EN04	17/06/09	Printable PDF forms	The RPH PDF form has the SCGH phone number, not the RPH one.	9/1/2009
EN05	18/06/09	Printable PDF forms	Printable Patient Discharge Note/Print Final Copies icons are inactive	9/1/2009
EN06	6/4/2009	IOL listing	Please add Alcon SN60T3, Alcon SN60T4 and Alcon SN60T5 to the IOL drop down list.	Added via Admin Console 27/08/2009
EN07	6/4/2009	Page Timer	Reset the timer to the maximum time with any mouse click/keyboard entry. Have the counter start at 35 mins (2100 secs). Currently 900 secs (15mins) when change pages only.	21/09/2009
EN08	15/7/2009	Theatre list page	Extra date appears, one day past date selected. Moves to bottom of page	27/08/09
EN09	16/7/2009	Assistant drop down list	Jonathon Ng appears twice, once is misspelt Jonathan	27/08/09
EN10	15/10/2008	Phacoemulsification template	IOL models not added - MC50BD, SN60AT, SA60AT, MA60MA, CZ70BD, MTA4UO, SN60WF, MA60AC	27/08/09 Added via Admin Console
EN11	15/10/2008	Phaco Template - Op details	Should be capsulotomy not capsulostomy	9/1/2009
EN12	7/11/2008	Phaco Template - Op details	Addition text box for lens and phaco machine type only works if the None type is selected from the drop down list. Need to create an 'other' type. Where is the added type stored?	
EN13	27/08/09	Provider table	Check with Jeff the difference in access between the General User and the Admin User.	17/09/2009

## Electronic Cataract Auditing Tool (eCAT) Maintenance Log

Error Number	Date Identified	Site of Error/Change	Brief Description of Error	Date finalised
EN22	14/9/2009	Operation Report	The operational reports at QE2 have a common number (730.1) down the side and the words <b>operational report</b> down the side of them. This allows them to be filed correctly apparently. Add this to the operational report for QE2.	
EN23	14/9/2009	Difficulties section of the Maintenance Module	Can't add a new <i>difficulty</i> to an existing <i>difficulty group</i> . The error reported is; <b>[Microsoft][ODBC SQL Server Driver] [SQL Server] Cannot insert the value NULL into column 'difDifficultyID', table 'CATS.dbo.tlu_Difficulty',column does not allow NULLS. INSERT fails.</b>	21/09/2009
EN24	14/9/2009	Difficulties section of the Maintenance Module	Similarly we couldn't add a new difficulty group either. The message was <b>[Microsoft][ODBC SQL Server Driver] [SQL Server] Cannot insert the value NULL into column 'digDifficultyGroupID', table 'CATS.dbo.tlu_DifficlutGroup',column does not allow NULLS. INSERT fails.</b>	21/09/2009
EN25	17/9/2009	Address section on Service Profile	Doesn't override the service address details even though the heading says "Only complete the following information if you want to display different details to that of the service on your reports."	
EN26	24/09/2009	Adding and editing a procedure	The boxes where there are arrows to allow increasing and decreasing of values only allow manual entry of data sometimes. All these number fields need to provide the option of manually entering data as well as the up and down arrows.	
EN27	24/09/2009	Blade size on Procedure page	When you select Blade Size to be to 2 decimal places on the template or the procedure forms, e.g. 2.75, it is rounded up to a whole number when you go back into the procedure again, e.g. the 2.75 becomes 3.00. Can this be fixed please?	
EN28	24/09/2009	Numerical entry boxes with up and down triangles	Some of the number boxes that have the small coloured triangles next to them for selecting numbers can also be typed directly into and some can't. Can we make it so that all of these boxes that have the triangles next to them can also have numbers typed directly into them please?	

## Electronic Cataract Auditing Tool (eCAT) Maintenance Log

Error Number	Date Identified	Site of Error/Change	Brief Description of Error	Date finalised
EN14	1/9/2009	All screens except the login in screen	eCAT becomes eCat on banner after login page.	
EN15	4/9/2009	Collapsible menus	When you close down the collapsible menus after ticking boxes the input is wiped out.	21/09/2009
EN16	4/9/2009	eCAT log in screen	Name not electronic Cataract auditing tool	
EN17	4/9/2009	Templates option on the ring menu	Can't add and save a template on the ring menu, though we can when going through the Add template option when a patient page is open.	17/09/2009
EN18	4/9/2009	Maintenance section	Need a section for maintaining reports. Two functions for this section - must be able to define what is printed out in each report, i.e. select the options to include, and also select which reports to print.	17/09/2009
EN19	4/9/2009	Printed reports	Take the dcotor's HE number off the report.	
EN20	14/9/2009	Templates/Medications section in Maintenance	When you tick any of the medications to be included in the template, then attempt to use the template to add a new procedure, the form stops at the section where the meds should come up. You don't get the bottom section of the form or any options to save. If you don't select any meds to be on your template then it is all hunky dory when you go to use the template to put in a procedure and you can save. The error that appears on the bottom of the report when you add meds to your template is; <b>ADODB.Recordset error 800a0cc1. Item cannot be found in the collection corresponding to the requested name on ordinal /cats/int_procedure.asp.line 5118</b>	17/09/2009
EN21	14/9/2009	Operation Report	In the Profile section where the operation report is that you can un-select items from it all works fine UNTIL you unselect the Intra-op medications (this is misspelt, you have inta instead of intra). Once you unselect the intra-op medications box, you get an error message next to the Immediate post-op meds line on the operational report and there is nothing after that. The error is; <b>Microsoft VBScript runtime error '800a01a8' Object required, /cats/int-procedure.asp,line 8826</b> . If you don't unselect this option everything works fine.	17/09/2009

## Appendix 4

# Public Hospital User Manual

### Electronic Cataract Auditing Tool (eCAT) Maintenance Log

Error Number	Date Identified	Site of Error/Change	Brief Description of Error	Date finalised
EN29	24/09/2009	Printed Operation Report	On the Operation Report, when you get the first preview, next to Operation Difficulties if you have selected None on the procedure then None is on the screen, but when you actually print the report instead of None you get --. Can we get the word None printed please?	
EN30	24/09/2009	Operation Report	The Operation Report prints all on one page nicely if you tick the option to include Intra-op medications on your service profile to include it in the report. If you don't tick the Intra-op meds option but then select options to be printed after that, then on the Operation Report you get the Operation Difficulties line printed then a page break then the other things that you selected on the next page. Not sure why this is but that's what happens.	
*****	Extracting data for personal auditing			

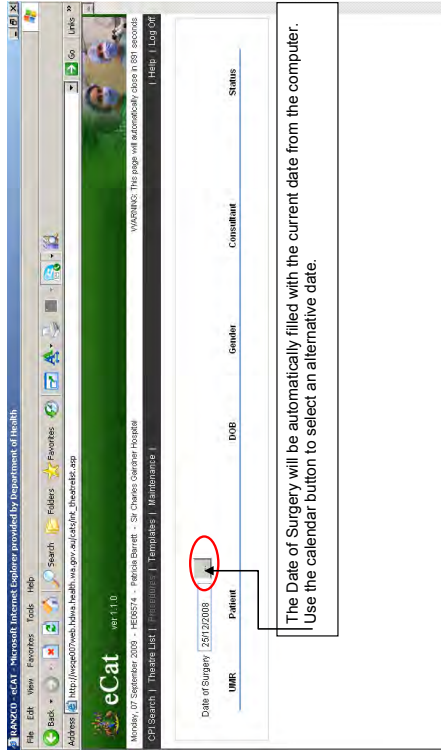
The Electronic Cataract Auditing Tool (eCAT) is a prospective cataract surgery registry set up in WA for clinical audit and outcomes research. It is an Australian first and will serve as a model for other States. A key feature of the registry is to provide readily accessible, valid and up-to-date information on a State-wide level. Data from the registry will complement the evidence base we have generated on the major sight threatening complications of cataract surgery from our previous research. This will be incorporated with the techniques we have developed for monitoring complications to provide a platform to improve the outcomes from cataract surgery and minimise the burden from complications.

This database has been designed to be used in theatre, where the data can be input directly by the surgeon performing the cataract surgery, or by one of the assisting doctor's. Database security is controlled via the Western Australian Health Department's unique staff number preceded by the letters HE. It is imperative that correct and complete data input into the eCAT system to ensure the best use of the information.

## 1. Accessing the cataract register

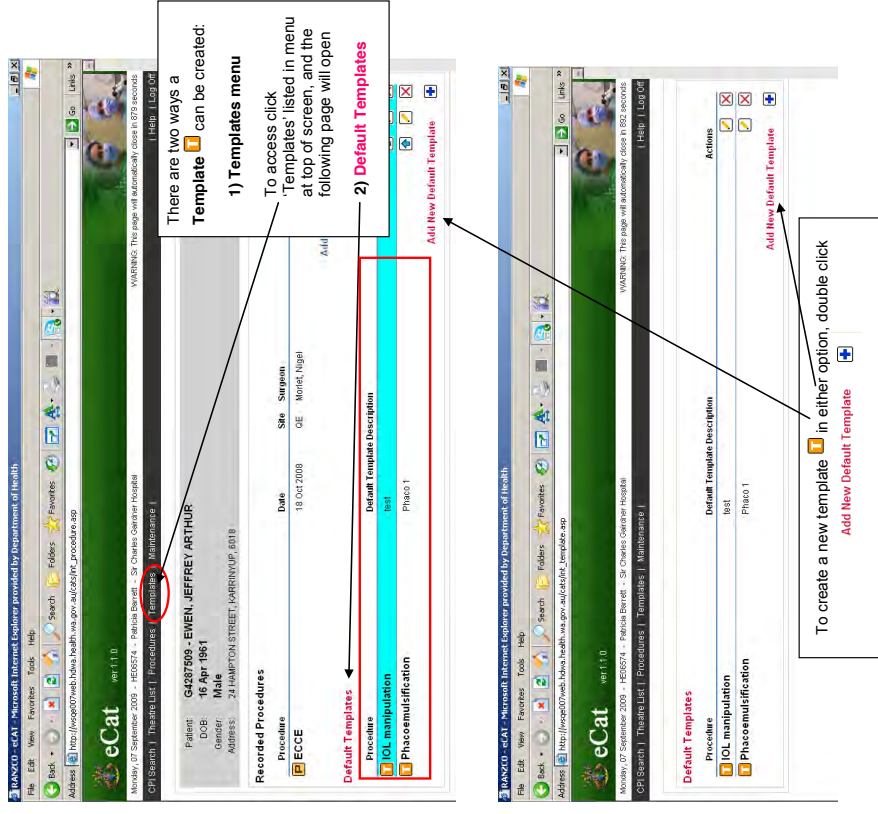
In the majority of cases, the patient data will be entered by picking the relevant patient from the theatre list, and then adding the cataract information in theatre.

## 2. Accessing the theatre list



Templates can be created to minimise the amount of data input required for each surgery. More than one template can be created and stored. Enter whatever information is constant for that procedure and then save the template with an appropriate name.

### 3. Creating a Template





#### 4. Recording a new procedure

Once the relevant patient has been picked from the theatre list, a new procedure detailing the information from the operation is created. This can be done either by using a default template, or entering a new procedure without a template.

The screenshot shows the eCat software interface. At the top, there's a navigation bar with 'eCat' and 'Microsoft Internet Explorer provided by Department of Health'. Below it is a toolbar with various icons. The main window displays the 'Recorded Procedures' table and the 'Default Templates' list.

**Recorded Procedures Table:**

Patient	Date	Site	Segment
G437609 - EWEN, JEFFREY ARTHUR	16 Apr 1961	DOB	
Gender: Male			
Address: 24 HAMPTON STREET, GARRINUP, ED18			

**Default Templates List:**

Procedure	Default Template Description
ECCE	test
	Phase 1

**Annotations:**

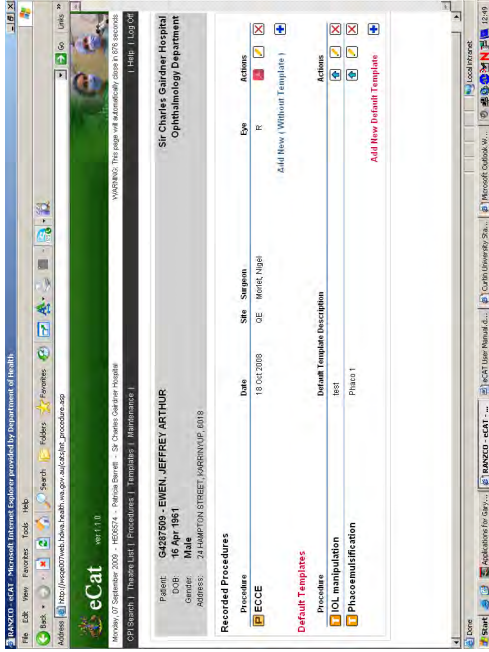
- To record a new procedure**
  - Without a template, double click **Add New (Without Template)**
  - Using a template, highlight and double click template name or click **Add New (Without Template)**
- Default Templates** (points to the 'Default Templates' list)
- Recorded Procedures** (points to the 'Recorded Procedures' table)

**Footer:** Microsoft, 12 September 2008 - 4502974 - Richard Sargent - St Charles General Hospital

[illegible][illegible]



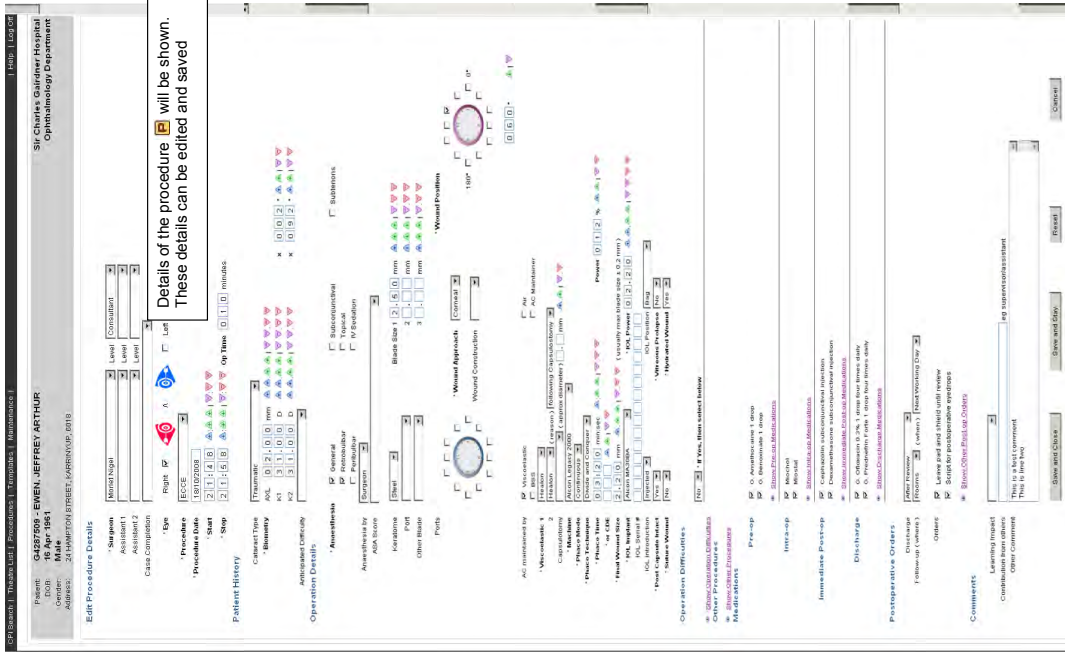




A patient's recorded procedure page will show:

- any historic procedures performed
- default templates you have available to use to enter this patient's procedure


To view a historic procedure double click on the given procedure



Details of the procedure will be shown. These details can be edited and saved



This is an example of the report that would be printed if the surgery was performed at the Eye Surgery Foundation.



Operation Report

OPHTHALMOLOGY DEPARTMENT  
EYE SURGERY FOUNDATION  
enquiries ph (06) 9000 0000  
Ref: UMR 54327508

Procedure Date:  
27 Aug 2009

Procedure:  
ICL Insertion

Other Procedures:  
Pupil Stretch, Full Hoods

Eye:  
Right

Surgeon:  
Ewen Jaffr - Training Registrar

Base Completion:  
Satisfactory Surgeon

Anaesthesia:  
Chemical

Wound Approach:  
OCB

Wound Protection:  
None

Vitreolysis T:  
None

Phaco Technique:  
Bowen

ICL Implant:  
None

ICL Power:  
11D

ICL Position:  
No

Post Capsule Intact:  
No

Vitreous Prolapse:  
No

Suture Wound:  
No

Hydrated Wound:  
No

Operation Difficulties:  
Anesthesia and Patient - Incomplete block - Minimal  
Anesthesia and Patient - Eye movement - Minimal  
Wounds - Unplanned suture required - Minimal  
Wounds - Excessive tear - Minimal  
Wounds - Excessive tear - Minimal  
G Cycloplegics 1% 1 drop

Intraop Medications:  
Baseline 5 conjunctiva  
Celestons subconjunctival injection

Postop Medications:  
Discharge After Review  
Celestons 1% 1 drop 4 times daily  
Organoid 0.5% 1 drop four times daily  
Sortal for postoperative eye drops

Discharge Medications:  
G Chloramphenicol 0.5% 1 drop four times daily  
G Cyclopentolate 0.5% 1 drop four times daily

Ewen Jaffr - Training Registrar  
Ophthalmology Department  
Eye Surgery Foundation

\*\*\* End of Report \*\*\*

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QEF04327508-2009/0081/3931454208

Page 1 of 1

7. Maintaining your Service Profile and changing the output for Operation Reports

All users have access to the Service Profile section of the cataract database. (Only users designated as Administrators can access the Maintenance section of the database).

BARCO - eCAT - Microsoft Internet Explorer

http://eocat07.vet.hva.se/health/vet\_gov/AutoCat/ICL\_templates.asp

Search

Back

Forward

Home

Print

Stop

Go

Address

Local intranet

ver 1.1.0

Thursday, 17 September 2009 - 16:02:14 - Petrusch Barrett - Royal North Hospital

CPH Search | Thesauri List | Procedures | Templates | **Service Profile** | Maintenance | Help | Log Off

Default Templates

Positions

ICL Insertion

ICL Manipulation

Phacomulsification

ICL Insertion

ICL Manipulation

Phase 1

Actions

ICL Insertion

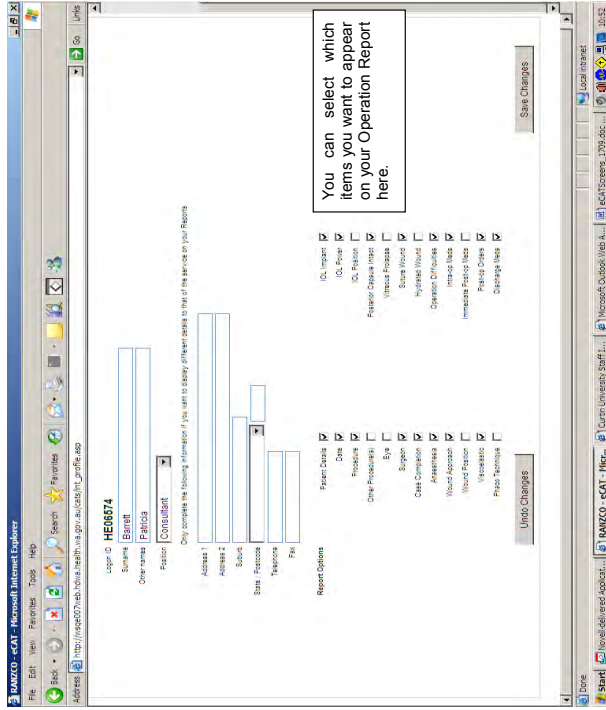
ICL Manipulation

Phase 1

Add New Default Template

You can alter your Profile by clicking on Service Profile on the top ring menu when you are on any screen.

The following screen appears when you click on the Service Profile button, showing the details of the person logged into the system.



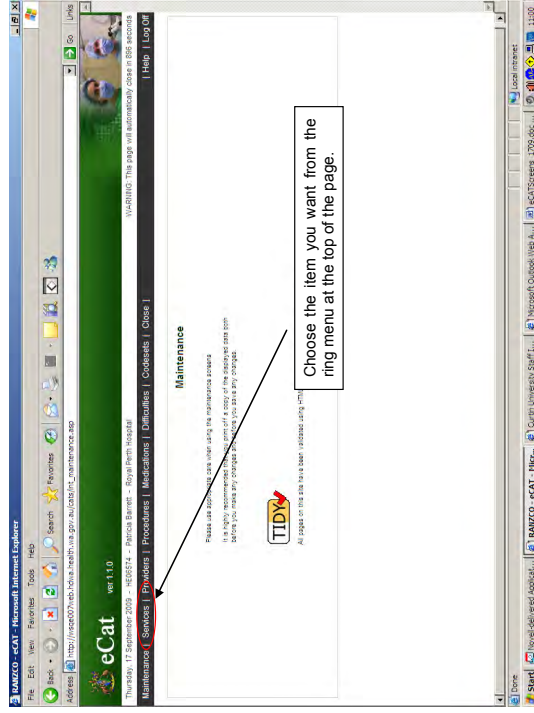
The default for all users is all the boxes ticked so that all possible elements print out on the Operation Report. Each user can select which items they want to print out for their report. If you select an item but do not enter that data into the procedure report then the heading prints but is blank next to it. Obviously, the data needs to be entered into the procedure section for the data to print here.

## Appendix 5

# Maintenance Manual (Under development)

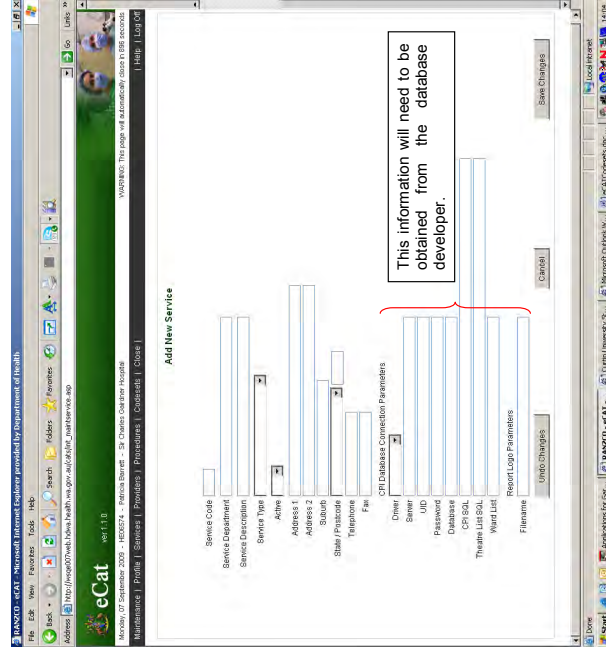
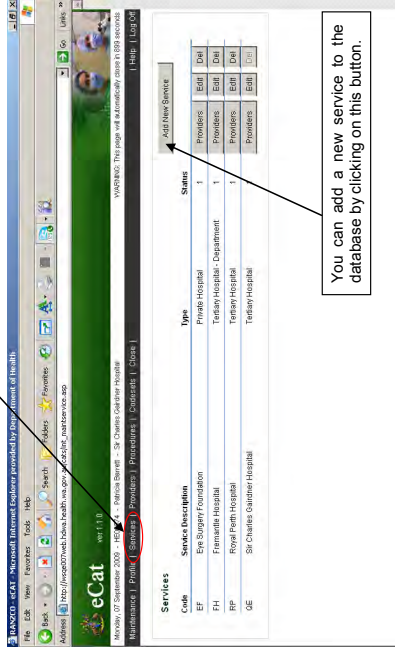


Users designated as Administrators have access to the Maintenance section of the eCAT system, General Users do not. If you are a General User and need to alter something using the maintenance section of the system, contact the administrator for your site.

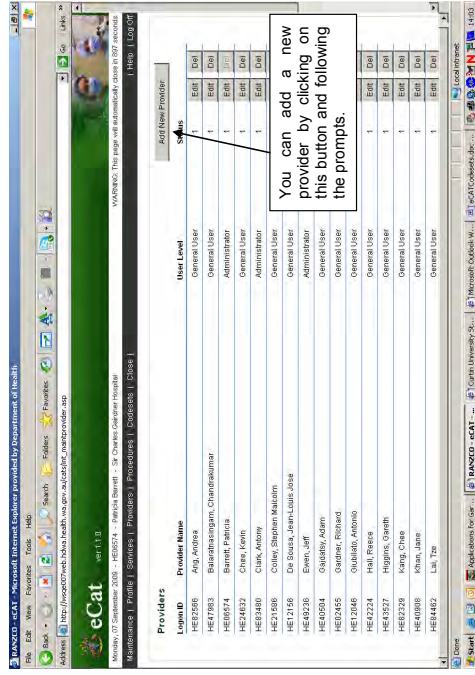


## 1. Adding a new service

To add a new service, click on Services on the ring menu at the top of the page.



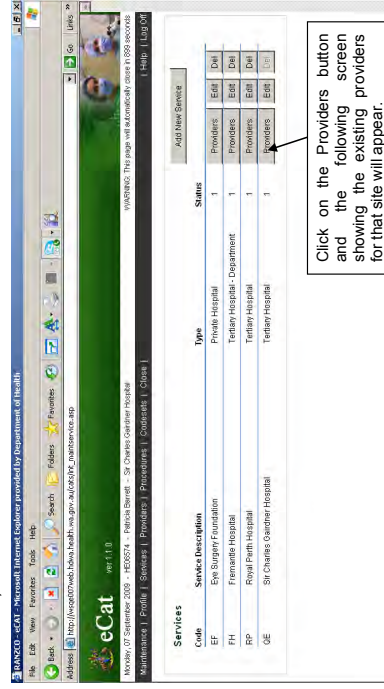
## 2. Adding a new provider



The screenshot shows the 'Providers' section of the eCat application. A table lists existing providers with columns for LoginID, Provider Name, User Level, and Status. A button labeled 'Add New Provider' is visible at the top right of the table. A callout box points to this button with the text: "You can add a new provider by clicking on this button and following the prompts."

LoginID	Provider Name	User Level	Status
HE32586	Ang, Andrea	General User	1
HE47983	Balarasasingam, Chandrasekhar	General User	1
HE89574	Barrett, Patricia	Administrator	1
HE24432	Chen, Kevin	General User	1
HE34480	Clark, Anthony	Administrator	1
HE21980	Colley, Stephen Malcolm	General User	1
HE12158	De Souza, Jean-Louis Jolys	General User	1
HE49236	Ewen, Jeff	Administrator	1
HE40504	Gajdhar, Adam	General User	1
HE2465	Gardner, Richard	General User	1
HE12046	Goulding, Anthony	General User	1
HE42224	Hall, Renee	General User	1
HE43527	Higgins, Gwath	General User	1
HE83226	Kiang, Chae	General User	1
HE40808	Khan, Jane	General User	1
HE84462	Lai, Tze	General User	1

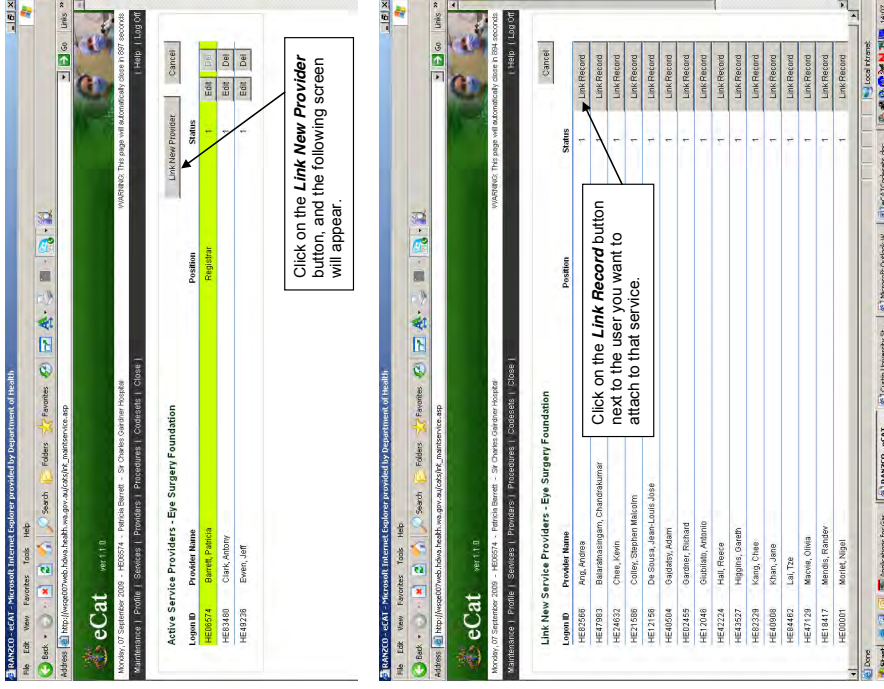
Once you have added a new provider, you will need to go to the services section as a user can not log in until they are attached to a service (A user can be associated with more than one service).



The screenshot shows the 'Services' section of the eCat application. A table lists existing services with columns for Code, Service Description, Type, and Status. A button labeled 'Add New Service' is visible at the top right of the table. A callout box points to this button with the text: "Click on the Providers button and the following screen showing the existing providers for that site will appear."

Code	Service Description	Type	Status
EF	Eye Surgery Foundation	Private Hospital	1
PH	Formative Hospital	Tertiary Hospital - Department	1
RP	Royal Path Hospital	Tertiary Hospital	1
GE	Sir Charles Gonsky Hospital	Tertiary Hospital	1

You can also add any existing users (providers) to a Service by clicking on this button and selecting the providers you want to add to that service.



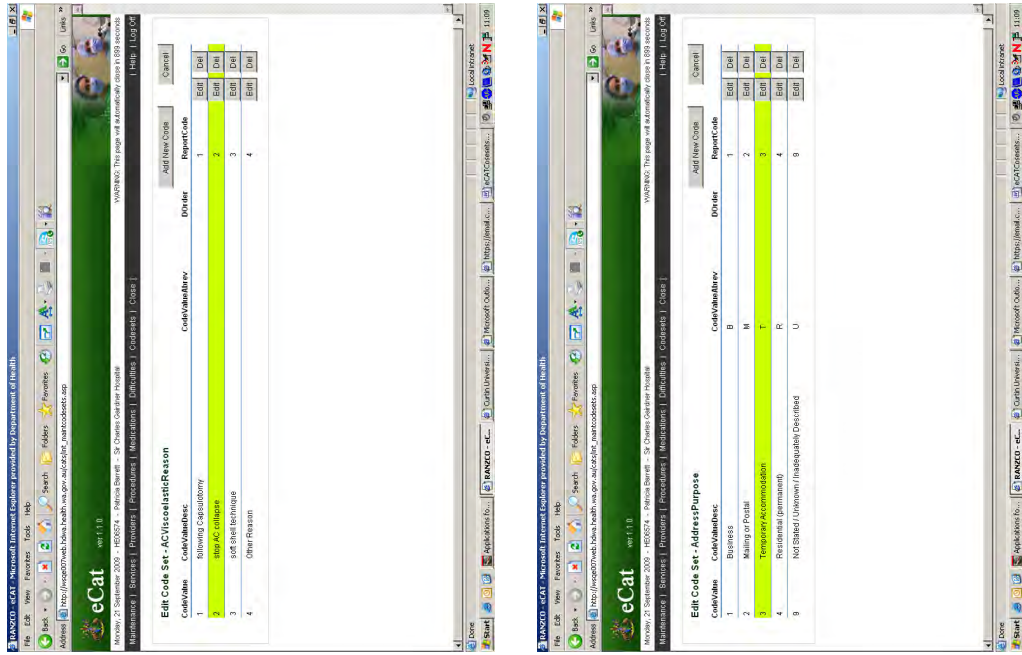
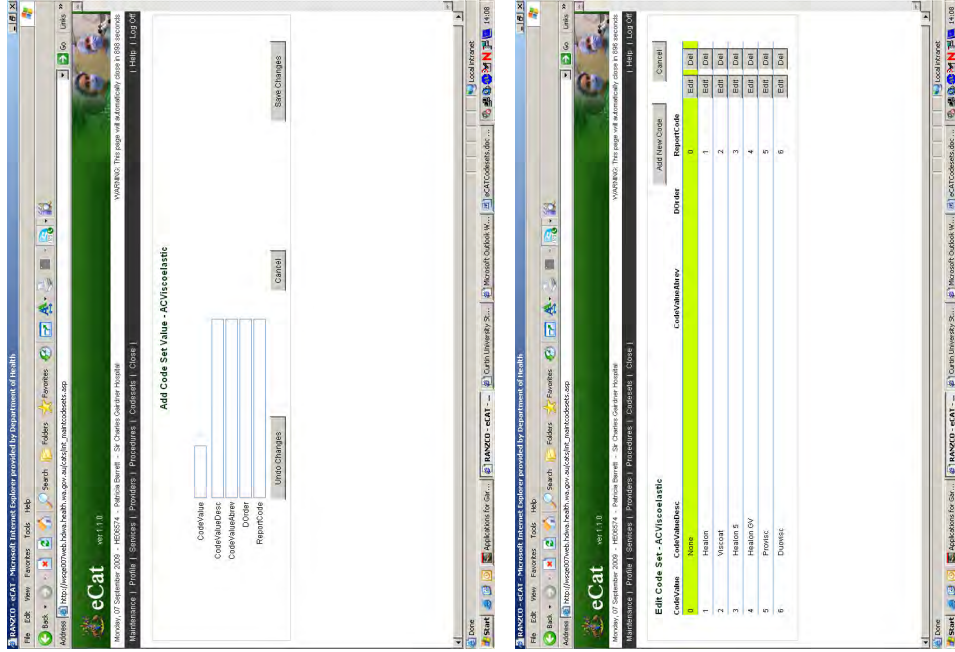
The first screenshot shows the 'Active Service Providers - Eye Surgery Foundation' screen. A table lists active providers with columns for LoginID, Provider Name, Position, and Status. A button labeled 'Link New Provider' is visible at the top right of the table. A callout box points to this button with the text: "Click on the Link New Provider button, and the following screen will appear."

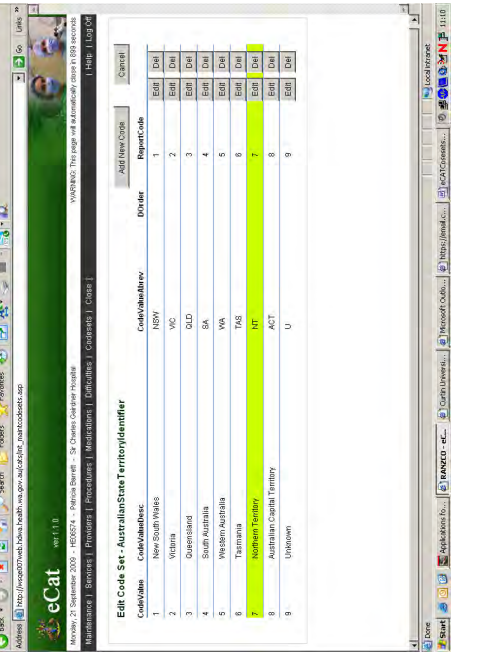
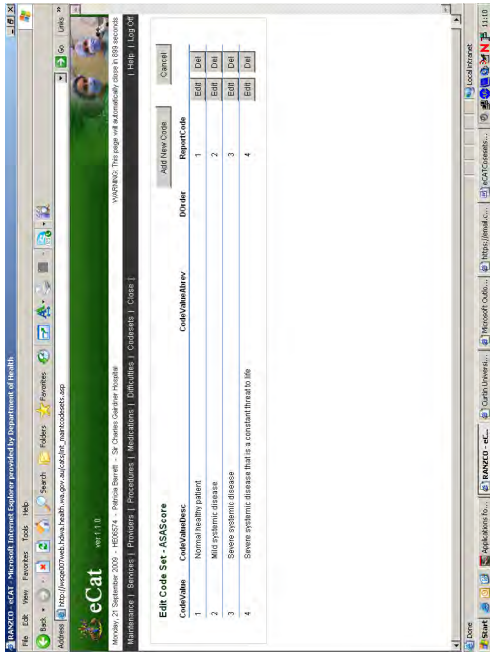
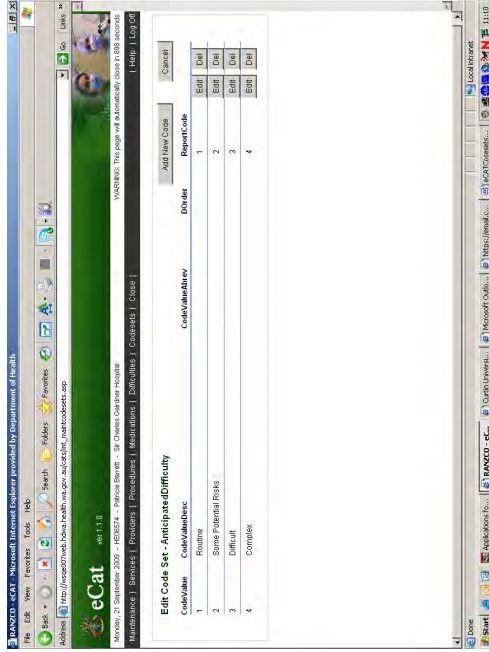
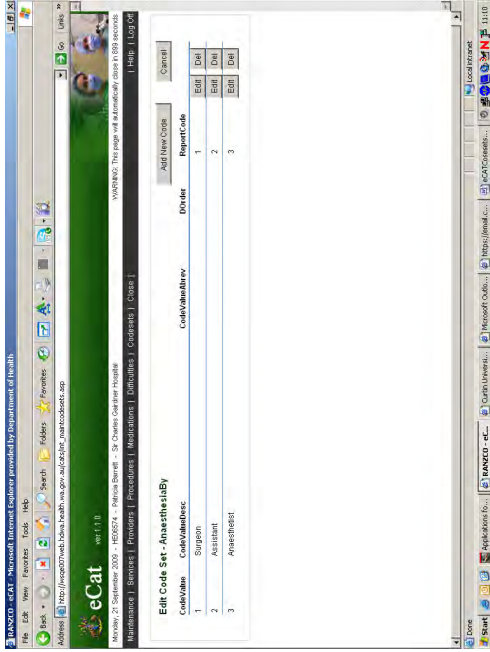
The second screenshot shows the 'Link New Service Providers - Eye Surgery Foundation' screen. A table lists providers with columns for LoginID, Provider Name, Position, and Status. A button labeled 'Link Record' is visible at the top right of the table. A callout box points to this button with the text: "Click on the Link Record button next to the user you want to attach to that service."

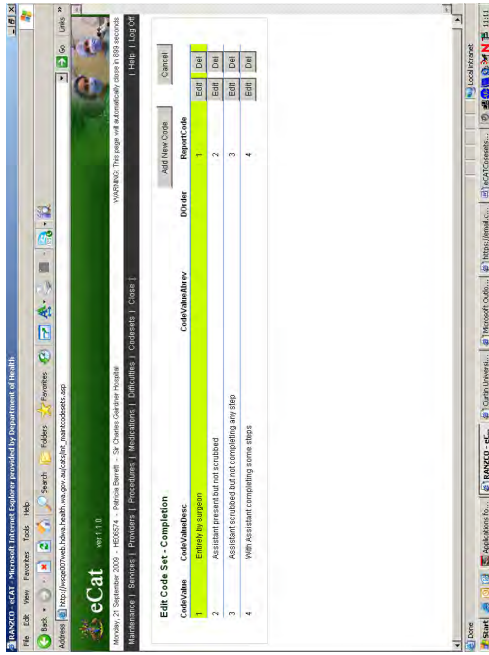
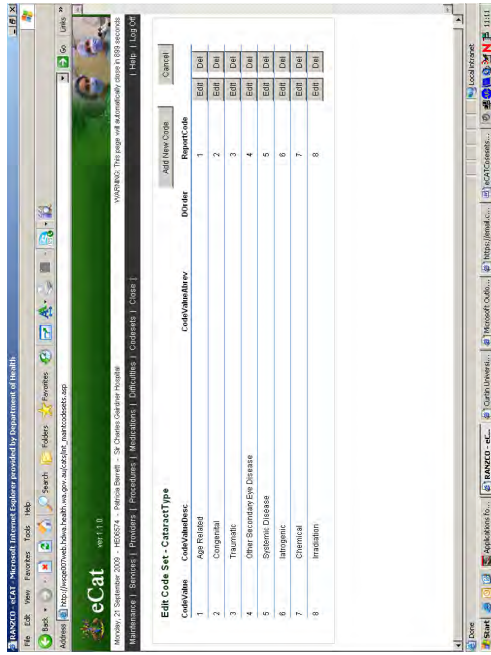
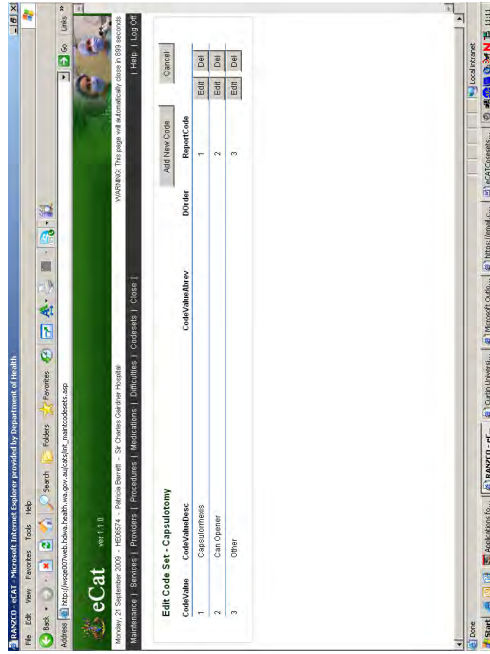
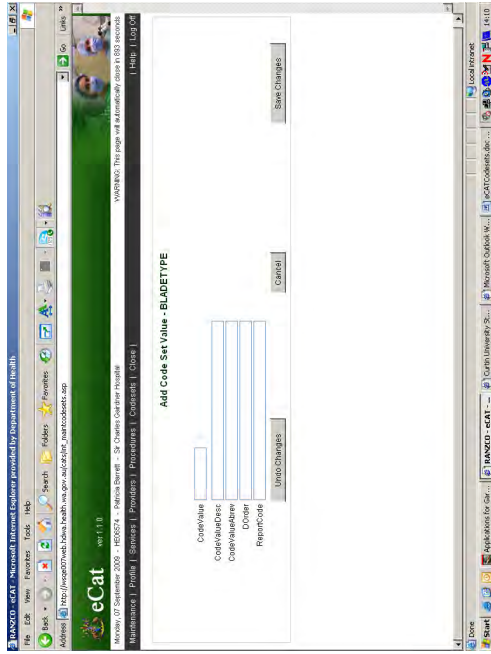
Now the user is active at the service that you have linked them to and can log in at that service.







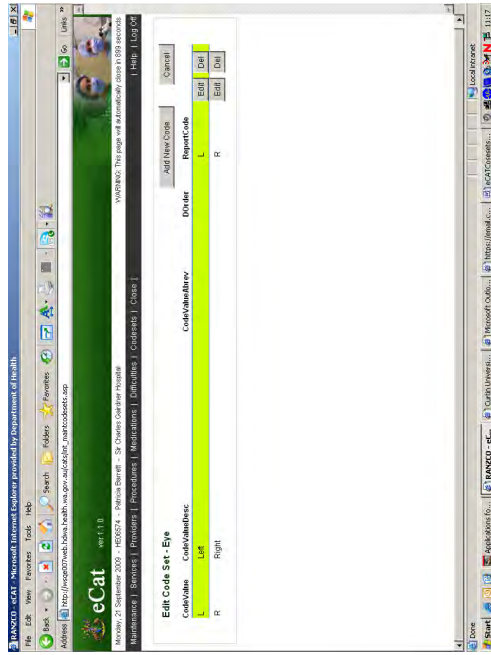
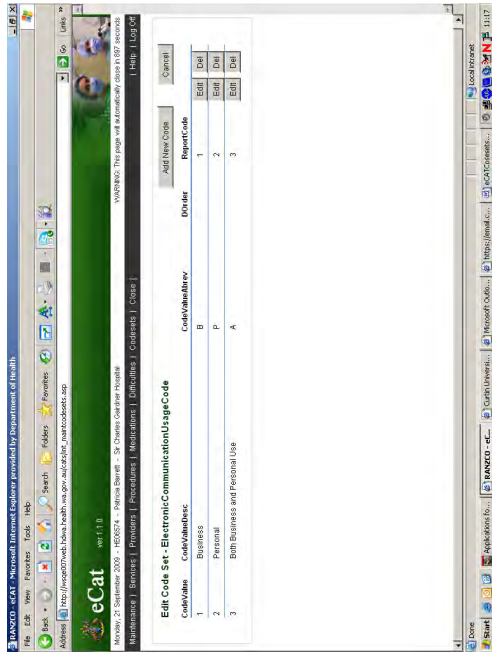
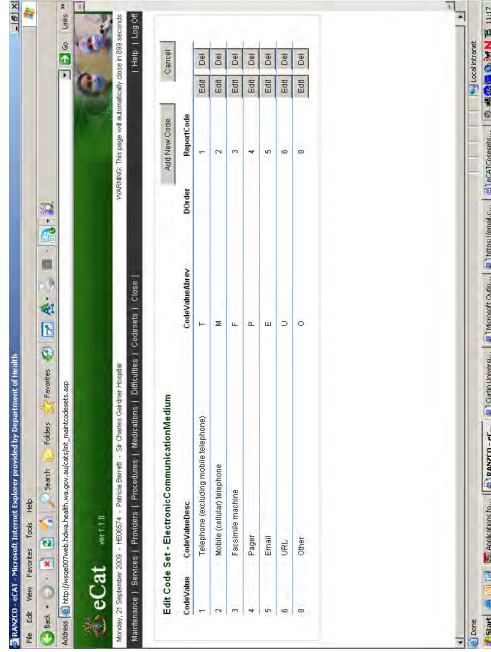
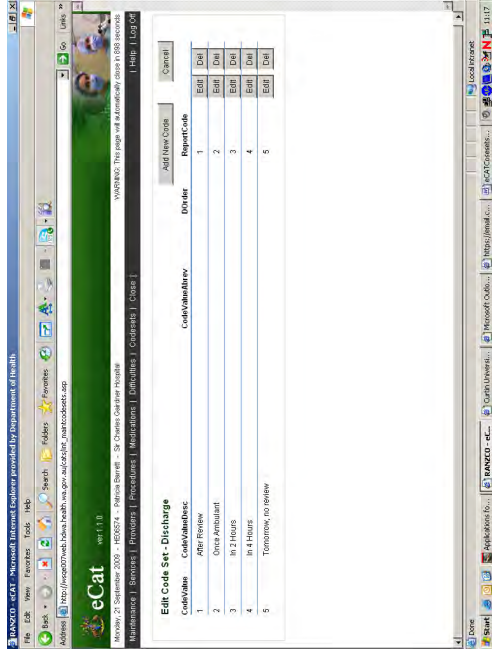


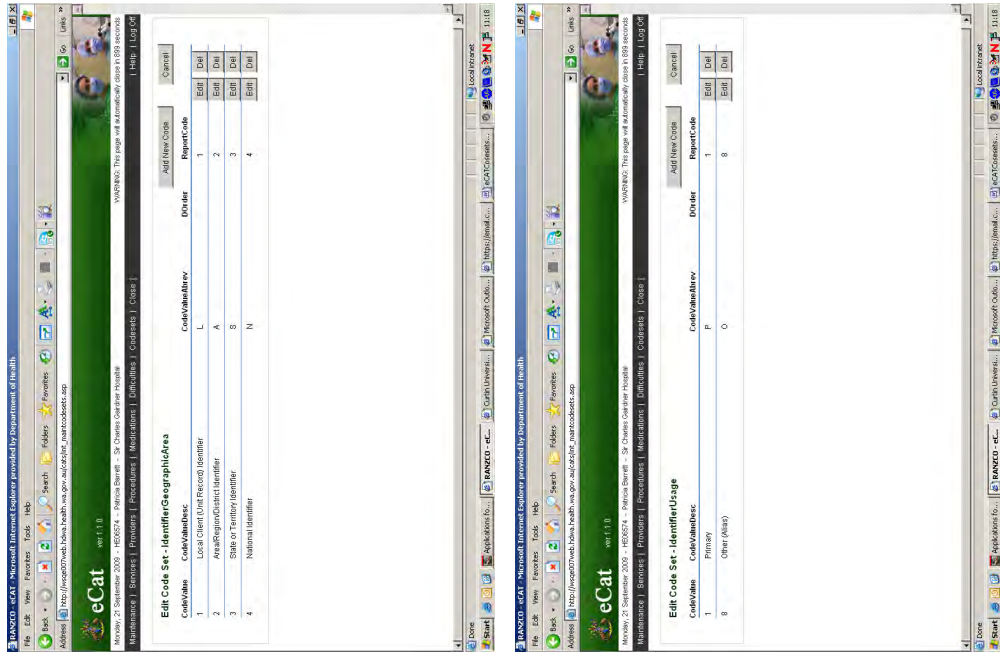


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Address: http://mango07web.health.wa.gov.au/efat/_indexcodeedit.asp					
Mango07 - 27 September 2007 - 405074 - Patients Search - 58 Changes Code per Month					
eCat ver 1.1.0					
Mainenance   Reports   Procedures   Medications   Calculators   Categories   Codes					
Edit Code Set - Country/Region					
Code/Value	Code/Value/Desc	Divisor	Parent Code	Code/Value/Desc	Divisor
1101	Australia	1	1101	Esti	Esti
1102	North Island	2	1102	Esti	Esti
1108	Australian External Territories, nec	1	1108	Esti	Esti
1201	New Zealand	2	1201	Esti	Esti
1301	New Caledonia	2	1301	Esti	Esti
1302	Papua New Guinea	2	1302	Esti	Esti
1303	S Solomon Islands	2	1303	Esti	Esti
1304	Vanuatu	2	1304	Esti	Esti
1401	Guam	2	1401	Esti	Esti
1402	Marshall Islands	2	1402	Esti	Esti
1403	Micronesia, Federated States of	2	1403	Esti	Esti
1404	Monrovia, Liberia	2	1404	Esti	Esti
1405	Nauru	2	1405	Esti	Esti
1406	Northern Mariana Islands	2	1406	Esti	Esti
1407	Palau	2	1407	Esti	Esti
1501	Cook Islands	2	1501	Esti	Esti
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1504	Niue	2	1504	Esti	Esti
1505	Samoa	2	1505	Esti	Esti
1506	South American	2	1506	Esti	Esti
1507	Vanuatu	2	1507	Esti	Esti
1508	Yonke	2	1508	Esti	Esti
1511	Yonke	2	1511	Esti	Esti
1512	Wallis and Futuna	2	1512	Esti	Esti
1598	Polynesia (excludes Hawaii, nec)	2	1598	Esti	Esti
1601	Asiatic Land France	2	1601	Esti	Esti
1602	Agassimon Islands, Territory	2	1602	Esti	Esti
1603	Aruba, Kingdom, Territory	1	1603	Esti	Esti
1604	Aruba, Kingdom, Territory	2	1604	Esti	Esti
1605	Chilean Antarctic Territory	2	1605	Esti	Esti
1606	Guernsey (New Zealand)	2	1606	Esti	Esti
1607	Ross Dependencies (New Zealand)	2	1607	Esti	Esti
2101	Channel Islands	2	2101	Esti	Esti
2102	England	2	2102	Esti	Esti
2103	Isle of Man	2	2103	Esti	Esti
2104	Northern Ireland	2	2104	Esti	Esti
2105	Scotland	2	2105	Esti	Esti
2106	Wales	2	2106	Esti	Esti
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2202	Belgium	2	2202	Esti	Esti
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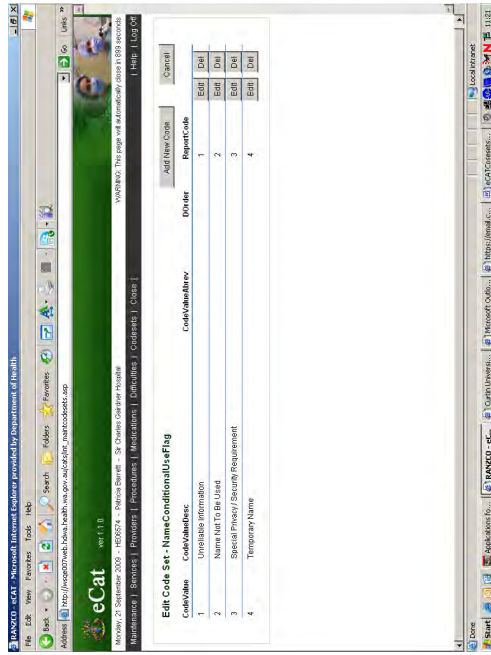
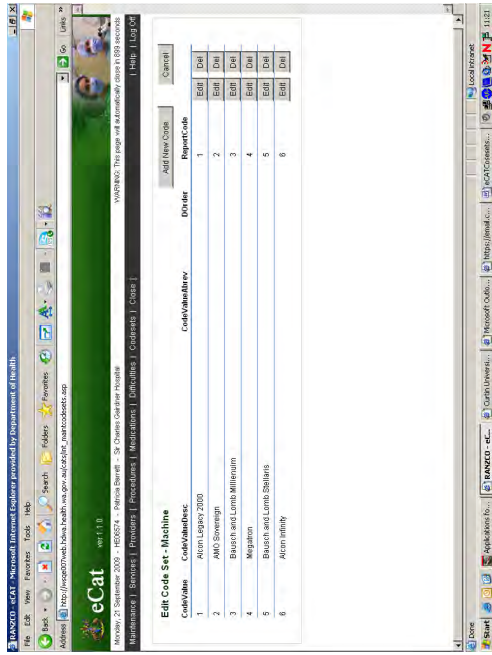
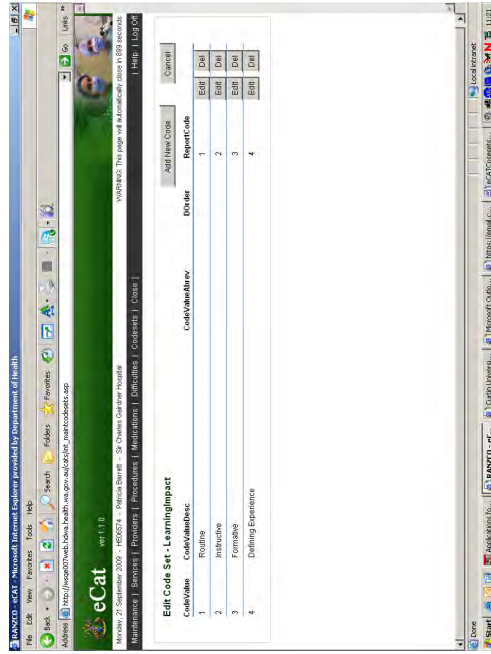
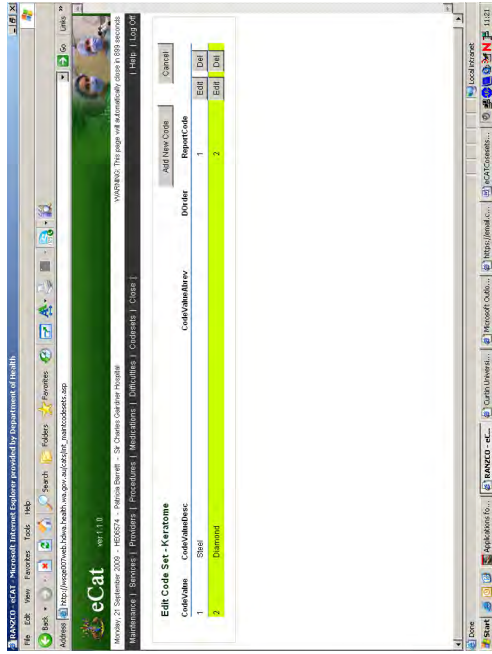
File	Edit	View	Resources	Tools	Help
Address: http://mango07web.health.wa.gov.au/efat/_indexcodeedit.asp					
Mango07 - 27 September 2007 - 405074 - Patients Search - 58 Changes Code per Month					
eCat ver 1.1.0					
Mainenance   Reports   Procedures   Medications   Calculators   Categories   Codes					
Edit Code Set - Database/Driver					
Code/Value	Code/Value/Desc	Divisor	Parent Code	Code/Value/Desc	Divisor
AAA	Day, month and year are accurate	AAA	Esti	Esti	Esti
AAE	Day and month are accurate, year is estimated	AAE	Esti	Esti	Esti
AUJ	Day and month are accurate, year is unknown	AUJ	Esti	Esti	Esti
AEA	Day is accurate, month is estimated, year is accurate	AEA	Esti	Esti	Esti
AEE	Day is accurate, month and year are estimated	AEE	Esti	Esti	Esti
AEU	Day is accurate, month is estimated, year is unknown	AEU	Esti	Esti	Esti
AUA	Day is accurate, month is unknown, year is accurate	AUA	Esti	Esti	Esti
AUE	Day is accurate, month is unknown, year is estimated	AUE	Esti	Esti	Esti
AUU	Day is accurate, month and year are unknown	AUU	Esti	Esti	Esti
EAA	Day is estimated, month and year are accurate	EAA	Esti	Esti	Esti
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EBA	Day and month are estimated, year is accurate	EBA	Esti	Esti	Esti
EEE	Day, month and year are estimated	EEE	Esti	Esti	Esti
EEU	Day and month are estimated, year is unknown	EEU	Esti	Esti	Esti
EUA	Day is estimated, month is unknown, year is accurate	EUA	Esti	Esti	Esti
EUU	Day is estimated, month is unknown, year is unknown	EUU	Esti	Esti	Esti
UAA	Day is unknown, month and year are accurate	UAA	Esti	Esti	Esti
UAE	Day is unknown, month is accurate, year is estimated	UAE	Esti	Esti	Esti
UAU	Day is unknown, month is accurate, year is unknown	UAU	Esti	Esti	Esti
UEA	Day is unknown, month is estimated, year is accurate	UEA	Esti	Esti	Esti
UEE	Day is unknown, month and year are estimated	UEE	Esti	Esti	Esti
UEU	Day is unknown, month is estimated, year is unknown	UEU	Esti	Esti	Esti
UUA	Day and month are unknown, year is accurate	UUA	Esti	Esti	Esti
UUE	Day and month are unknown, year is estimated	UUE	Esti	Esti	Esti
UUU	Day, month and year are unknown	UUU	Esti	Esti	Esti







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Internet Explorer window showing the eCat application. The address bar displays: [http://ncsc07web.hhs.gov/subcat/ncsc\\_accounts.asp](http://ncsc07web.hhs.gov/subcat/ncsc_accounts.asp). The page title is "eCat ver 1.1.0". The main content area shows the "Edit Code Set - Name/Usage" dialog box.

**Edit Code Set - Name/Usage**

Code/Value	Code/Value/Desc	Order	Report Code
1	Registered Nurse (English Name)	L	Edit Del
2	Registered Nurse	R	Edit Del
3	Nurse Practitioner	N	Edit Del
4	Physician Assistant	P	Edit Del
5	Medical Nurse (Name at Birth)	M	Edit Del
6	Other Name (Name)	O	Edit Del

Internet Explorer window showing the eCat application. The address bar displays: [http://ncsc07web.hhs.gov/subcat/ncsc\\_accounts.asp](http://ncsc07web.hhs.gov/subcat/ncsc_accounts.asp). The page title is "eCat ver 1.1.0". The main content area shows the "Edit Code Set - Source/Code/Modification" dialog box.

**Edit Code Set - Source/Code/Modification**

Code/Value	Code/Value/Desc	Order	Report Code
1	Official Death Certificate of Death Registrar	1	Edit Del
2	Health Care Provider	2	Edit Del
3	Relative	3	Edit Del
4	Other	4	Edit Del
5	Unknown	5	Edit Del

## **Appendix 4: The National Eye Health Initiative Eye Demonstration Grants (Round 2) Application**

EYE HEALTH DEMONSTRATION GRANTS PROGRAM

FUNDING ROUND TWO (NEHI/02)

APPLICATION FOR FUNDING

Summary

Organisation:  
Centre for Health Services Research, The University of Western Australia (UWA)

Name of Project:  
Monitoring cataract surgery outcomes in Western Australia: establishing a State-wide cataract surgery registry

Amount of Funding Sought:  
\$148, 984

Duration of Project (years/months):  
12 months

Brief summary of the Project:

Cataract surgery is the commonest operative procedure performed and expanding at 6 to 8% per annum as the population ages. Concomitant with this increase, blinding complications will become much more prevalent.

We reviewed over 20 years of cataract surgery operations (examining over 10,000 case notes) using the Western Australian (WA) data linkage system to determine the extent of serious complications. Using those data as prior probabilities, we developed statistical models for real-time prospective monitoring of complications. To vastly improve the operative record we designed a web-browser based data-entry form for use in theatre. These capabilities are not available elsewhere, nor do other States have a population-based infrastructure to capture such data.

Using these tools we wish to implement a population-wide cataract surgery registry in WA to monitor surgical outcomes. By identifying risks and monitoring adverse events we hope to improve cataract surgery outcomes and minimise the risk of iatrogenic blindness.

You must refer to the Application Guidelines when completing this Application form. It is your responsibility to ensure that your application complies fully with the Guidelines.

**Due date for submissions is 5.00pm Eastern Standard Time  
Friday 26 October 2007.**

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PART TWO – FUNDING REQUEST

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- 1.3 Identification of unmet need/s
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ASSESSMENT CRITERION 3 –ABILITY

- 2.5 Objectives, key activities and timeframe
- 2.6 Project management
- 2.7 Financial management
- 2.8 Budget
- 2.9 Organisational support
- 2.10 Monitoring
- 2.11 Evaluation

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ATTACHMENT A: REFEREE TEMPLATE

ATTACHMENT B: National Framework for Action to Promote Eye Health and Prevent Avoidable Blindness and Vision Loss

ATTACHMENT C: Eye Health in Australia

## Part One – Organisation's Details

### 1.1 Details of Organisation

Legal name – The University of Western Australia
Please provide the trading or business name (or short name), if applicable - The University of Western Australia
Please provide the Australian Business Number (ABN) - 37-882-817-280
Please provide the Australian Company Number (ACN), if applicable -
Please provide the business entity type. For example: a company, an incorporated association, a body incorporated under other legislation. Public Educational Institution
Is the organisation registered for GST? YES

### 1.2 Type of Organisation (you may tick more than one box)

<input type="checkbox"/> Non-profit/charitable organisation	
<input type="checkbox"/> For profit organisation	
<input type="checkbox"/> Non-government health care provider	
<input type="checkbox"/> Government funded health care provider	
<input type="checkbox"/> Professional association	
<input type="checkbox"/> Aboriginal or Torres Strait Islander organisation	
<input checked="" type="checkbox"/> Other (please specify) Public Educational Institution - University	

### 1.3 Brief description of your organisation's main functions and activities

The Health Services Research (HSR) programme in WA is a leader in its field in Australia. It has become increasingly known to health services researchers around the world due to its work with population-based linked health data evaluation of health services, patient safety, surgical care and pharmaco-epidemiology – it includes the WA Safety and Quality of Surgical Care Project. From 2007 the HSR programme has extended its scope to include Curtin University after Professor Semmens relocated with his team by accepting the inaugural chair in Health Service Research in Western Australia. A close collaborative alliance has been maintained.

The HSR programme supports research through the creation and maintenance of data and technical infrastructure, facilitation of a network of collaborators and provision of training opportunities. Two themes direct the research program. The first focuses on health conditions that are important by reason of their frequency, their contribution to mortality or disability, the scope they offer for intervention, best practice treatment pathways and the level of health resources they consume. The second focuses on a whole-of-population approach to research to avoid the selection and referral biases that may affect studies based in single institutions.

### 1.4 Address of Organisation

Registered Office Address	Centre for Health Services Research School of Population Health The University of Western Australia Crawley		
Suburb/Town			
State	Western Australia	Postcode	6009

Street Address	Centre for Health Services Research School of Population Health The University of Western Australia 35 Stirling Highway Crawley		
Suburb/Town			
State	Western Australia	Postcode	6009

Postal Address	As Above		
Suburb/Town			
State			

### 1.5 Authorised Contact Persons

Title and Name	Preferred Contact	Alternative Contact	Alternative Contact
Dr David Preen	Professor James Semmens	A/Professor Nigel Morlet	
Official Position	Director, Centre for Health Services Research, UWA	Director, Health Services Research, Curtin University	Adjunct Associate Professor, Health Services Research, Curtin University
Telephone number	08-6488 1307	08-92661856	08-92856665
Facsimile number		08-9266 1866	08-9266 1866
Email address	david.preen@uwa.edu.au	james.semmens@curtin.edu.au	n.morlet@idrs.com.au
Please provide your preferred method of communication.	Telephone	Telephone	Telephone

### 1.6 Joint Applications

Is this a joint application with other organisation/s? Yes

If YES, please list the other organisation/s here.

Health Services Research, School of Public Health, Curtin University of Technology

## Part Two – Funding Request

### ASSESSMENT CRITERION 1 – CONSISTENCY WITH NATIONAL EYE HEALTH FRAMEWORK

#### 2.1 Describe the project you propose to fund with this grant.

<b>Name of the project:</b>	Monitoring cataract surgery outcomes in Western Australia: establishing a State-wide cataract surgery registry
	We propose to pilot the establishment of a cataract surgery registry in a cross section of hospitals in Western Australia (WA) to monitor outcomes and adverse events. We have already developed an advanced browser-based software system specifically for this purpose (see <a href="http://130.94.842.1">http://130.94.842.1</a> ). Cataract operative data will be recorded and collated in a database that will remain within each participating hospital. Through data linkage processes that are well established in WA, we will be able to undertake database research in a de-identified manner. This project builds upon our expertise from two previous NHMRC funded research into the major sight threatening complications of cataract surgery in WA [Appendix A]. It represents a natural progression of our work and will continue our commitment to ongoing research of cataract surgery outcomes in WA.
<b>The specific aims of the project are to:</b>	
1.	Implement a web-based registry of cataract surgery in a cross section of WA hospitals.
2.	Use this cataract surgery registry to collect prospective data on cataract surgery procedures performed in WA.
3.	Determine the usefulness of the registry in assessing selected outcomes of cataract surgery in a cross-section of WA hospitals with a pilot study.
	Physical address of facility where project will be undertaken: The University of Western Australia, Western Australia
	Population and/or geographical area the project will cover/service: All of Western Australia
	Estimated number of patients /families/carers to be assisted: All Western Australians who will require cataract surgery in the future will be assisted by this study, currently ~14, 000 people per year.

#### 2.2 Describe how the proposed project furthers the aims and objectives of the National Eye Health Framework. 600 words

There are currently no State-wide cataract surgery registries in Australia. Our plan to establish a prospective cataract surgery registry in WA for clinical audit and outcomes research will be an Australian first and serve as a model for other States. A key feature of the registry will be to provide readily accessible, valid and up-to-date information on a State-wide level. Data from the registry will complement the evidence base we have generated on the major sight threatening complications of cataract surgery from our previous research. This will be incorporated with the techniques we have developed for monitoring complications to provide

a platform to improve the outcomes from cataract surgery and minimise the burden from complications.

In establishing the registry, several key areas for action outlined in the National Eye Health Framework will be addressed:

1. **Improving the evidence base and reducing the risk:** We aim to reduce the risk of adverse outcomes of cataract surgery by providing a more robust evidence base to identify clinical factors that may be associated with adverse outcomes. Operative factors such as intra-ocular lens type, incision location and use of antibiotics are not routinely collected for analysis, yet are very important because they can affect the risk of adverse outcomes. Timely availability of this information will improve our ability to provide ophthalmologists with the appropriate evidence to ensure best quality clinical practice and reduce the risk of iatrogenic vision loss and blindness.

The planned prospective data collection in this registry will also improve our ability to detect trends in adverse events earlier than was previously possible. Currently we are confined to retrospective studies with chart review, and any excessive adverse events are often detected years later. The cataract registry in conjunction with our knowledge of prior probabilities of major complications and the statistical techniques for monitoring, such as the cumulative sum chart, will allow us to observe trends and identify problems earlier and thereby minimise harm from further adverse events due to late detection.

2. **Improving the systems and quality of care:** The quality of health care may be defined as “the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge”. Each medical intervention requires its own measurements of quality. The proposed cataract surgery registry represents a step towards greater use of electronic tools in routine clinical management and a significant improvement in the current system and quality of care for cataract surgery in WA. Data from the registry will allow the impact of important surgical factors on clinical outcomes to be measured. The proposed system will standardise operative documentation for cataract surgery. Timely analysis of the data using techniques such as cumulative sum charts will provide earlier warnings of excessive adverse events after cataract surgery.

3. **Improving access to eye health care services:** Access to cataract surgery will be better assessed through a prospective state-wide cataract surgery registry. Trends in cataract surgery will be easily identified in addition to various clinical factors associated with these. Researchers will be able to identify patient groups who are poorly represented in the system and thus improve our ability to identify and address barriers to cataract surgery in WA.

## ASSESSMENT CRITERION 2 – NEED FOR PROJECT

### 2.3 Why is this project needed? How have you assessed the need/s and determined that you will meet them? 600 words

Cataract surgery is the most commonly performed operation in Australia.<sup>1</sup> Whilst complications are uncommon, they can lead to worse visual outcomes and even blindness. Over the next decade the number of cataract procedures performed each year, along with the number of complications, is expected to double as a result of our ageing population. The burden of visual impairment due to adverse outcomes of cataract surgery is therefore likely to become even more important in the future.

The HSR group, through the Endophthalmitis Population Study of Western Australia (EPSWA), has extensively examined trends in cataract surgery and its outcomes in WA with the support of NHMRC grants totalling over \$500,000. This work has laid the foundation to i) establish the need for a whole-population cataract surgery registry in WA, and ii) provide the evidence-base needed to support such a registry. An overview of the research output from our group is provided in Appendix A.

To summarise, we used whole-population methodology (supported by the Western Australian Data Linkage System (WADLS) [Appendix B]) to extensively evaluate cataract surgery trends in WA and the incidence of adverse outcomes – particularly endophthalmitis. We were able to show that the number of cataract procedures in WA has increased dramatically by 6% per annum over the last 20 years from 1,321 in 1980 to 12,925 in 2001. We also showed that postoperative endophthalmitis occurs in as many as one in five hundred cataract cases, resulting in around 250 cases of postoperative endophthalmitis in Australia each year. Furthermore this complication has increased in parallel with the 6% annual increase in cataract surgery over the last 20 years. More recently we have described trends in other sight threatening complications of cataract surgery including dropped nucleus, retinal detachment, IOL dislocation, pseudophakic bullous keratopathy and wound dehiscence over the same period. As a result of these studies we have developed an extensively validated database of all cataract surgery complications since 1980.

Whilst we have been able to quantify the importance of complications after cataract surgery for the entire WA population, our work also highlighted the need for ongoing monitoring of cataract surgery outcomes to continually improve the quality of care we provide. However, through our work we have also demonstrated why a State-wide cataract surgery registry is necessary in order to achieve this:

**Cataract operation details are generally poorly recorded:** Hospital administrative databases do not record laterality or basic operative information. We also found that there can be systematic errors in coding. For example, phacoemulsification surgery was commonly mis-coded as extracapsular surgery during the early 1990s when phacoemulsification was first introduced [Appendix A]. Even chart review, often considered the gold standard, is not sufficient since the level of detail recorded on operation sheets is extremely variable and clinically important information is often not recorded eg type of incision. Without this information, we cannot comment upon the impact of operative factors on the outcomes of cataract surgery.

**Information is not readily accessible:** In our work, we established that extensive manpower is needed to validate operative information from every potential cataract procedure complication. In validating the sight-threatening complications of cataract surgery we reviewed close to 10,000 medical records from hospitals across the state. It is simply not feasible to do so on an ongoing basis.

**Information is not up-to-date:** Our evaluation of cataract surgery in WA has been the culmination of years of extensive work and, whilst it has provided very useful information, it is based on data from up to 27 years ago. If we are to continue monitoring cataract surgery outcomes in WA and provide up-to-date data, then we need to develop a system whereby contemporary detailed operative information can be accessed efficiently.

Our proposal to implement a prospective cataract surgery registry will overcome the deficiencies found with our current data sets by requesting basic operative information from every cataract operation performed in WA. This will provide the information required for assessment of operative factors on cataract surgery outcomes in a standardised format that is readily accessible, up-to-date and validated.

1. Australian Institute of Health and Welfare. 2005. Vision Problems Among Older Australians. Bulletin no.27 AIHW cat. No. Aus 60. Canberra: AIHW.

### 2.4 How will the project complement other eye health care services, activities and resources nationally, regionally or in your local area? What links (if any) with other eye health care activities and services will the proposed project create or enhance? 900 words

WA is in a unique position to benefit more than any other state in Australia from a cataract registry due to the research infrastructure afforded by the WA data linkage system [Appendix B]. The proposed registry will contribute to the wealth of data already contained with the WADLS that will further its utility to provide quality, population-based research into eye health with particular focus on cataract. As far as we are aware, in establishing this registry, we will be creating the first system of its kind anywhere in the world. Furthermore, our group is in the process of validating the state blind registry at the WA Association for the Blind with the aim of subsequently linking this with the WADLS. This project, known as the Epidemiology of Blinding Eye Disease Study, will represent the world's most comprehensive complete, whole-population blind register. It's linkage with the WADLS will, for the first time anywhere in the world, allow us to directly link cataract surgery and blindness for an entire population. This is an exciting concept not only for eye health service research in WA but also for Australia and the international eye care community.

In conducting the proposed project we will develop active linkages between the local research community responsible for evaluating health service outcomes and the health services that provide them. As the culture of health care systems place more emphasis on the importance of clinical audit and reporting to improve the safety and quality of health care, there is an increasing need for collaboration between health researchers and service providers. Through these linkages we will be able to establish the needs of health service providers and subsequently develop an active feedback loop whereby we can provide the information they need to assess their cataract surgery service.

There is a general national, indeed international, drive towards innovation in e-health technology and integration with the health system to help improve health service delivery and the safety and quality of health care. The UK National Health Service has already begun the process of developing their own national cataract dataset for the very reasons we have outlined.<sup>1</sup> We feel our proposed project will contribute significantly towards ensuring WA maintains its standards for international excellence in health care by developing it's own. Furthermore, the WA experience will likely serve to provide a foundation upon which other State registries, or even a national register, may be developed.

1. Johnston RL, Sparrow JM, Canning CR, Toole D, Price NC. Pilot National Electronic Cataract Surgery Survey: I. Method, descriptive, and process features. Eye 2005;19(7):788-94.

## ASSESSMENT CRITERION 3 - ABILITY

### 2.5 Objectives, Key Activities, Timeframe:

What are your objectives for this project?	What are the key activities you intend to undertake to meet these objectives?	How will you know if you have achieved your objectives?	Duration	Completion Date
1. Implement the browser-based software system to the pilot hospitals: - Royal Perth Hospital, Sir Charles Gairdner Hospital, Fremantle Hospital, Lions Eye Institute, Eye Surgery Foundation, Bunbury Hospital, St John of God Subiaco, St John of God Bunbury, Swan District Hospital, Bentley Hospital and Osborne Park Hospital	Liaise with hospital departments and ophthalmologists to install the web-based software (and computer portals if needed) in theatres at each hospital		3 months	01/07/2008
3 Promote and train clinical staff in the use of the software system	Presentation evening to launch and promote the use of the web-based software On site training of ophthalmologists – one on one Provide ongoing support for clinical staff	Information from all cataract operations in all pilot hospitals will be represented correctly in the registry.	6 months	01/10/2008
4 Collection and analysis of outcome data	Interrogate the cataract surgery registry and collate initial data	We will have aggregated results from data analysis	12 months	01/04/2009
5. Conduct validation and integrity studies	Sample the registry and conduct case-note and other record review	Comparative results, with objectives above	12 months	01/04/2009

### 2.6 Project Management

A full time project manager will be employed to oversee the implementation of the web-based registry to the pilot hospitals and the day to day functioning of the project. In particular, this will involve liaising with hospital departments and ophthalmologists to ensure smooth running of the project. They will also be responsible for providing software training for users and, thereafter, ongoing technical support.

Overall project management responsibility will reside with Dr David Preen, Professor James Semmens, A/Professor Nigel Morlet and Dr Antony Clark. Preen and Semmens have a strong background in health services research and epidemiology. Morlet is a practicing clinical ophthalmologist with a long track record in ophthalmic epidemiology research. Clark is a graduated from medicine with honours in 2004 and is currently undertaking a doctorate degree in ophthalmic epidemiology. Semmens, Preen and Morlet have extensive experience in research project management gained from being party to 20 NHMRC grants, 10 as principal investigators, as well as a variety of projects funded through other sources. Semmens is the initiator and Director of the WA Safety and Quality of Surgical Care Project and collaborated with Morlet since 1998 to run an ophthalmology research program which has investigated the trends, service utilisation and outcomes of eye surgery in WA, with a particular focus on endophthalmitis. Project management has included gaining research fund from the NHMRC and industry, employing and training quality staff, establishing the research design, providing ethics approval, employment and training of staff, data analysis supervision, and publication of outcomes. Preen is the Director of the UWA Centre for Health Services Research and currently manages 15 full-time staff and 12 postgraduate research students. Further, Dr Preen has gained competitive research funding totalling ~\$2.5 million from organisations such as the NHMRC, WA Department of Health and National Prescribing Service. Consequently, he has been responsible for conception of research protocols, gaining ethics approvals, employment and training of research staff, data analysis supervision, and dissemination of outcomes. Clark is currently employed under a NHMRC grant to evaluate eye service provision in and the adequacy of diabetic retinopathy screening WA. He is also responsible for the coordination of the group's ophthalmic research programme.

Monthly meetings will be convened to discuss project management, budget responsibility and other issues that may arise.

### 2.7 Financial Management

The HSR group has extensive experience with financial management of research projects which cover around \$18.5 million and includes a team of around 16 experienced researchers and supporting adjuncts. We have gained around \$1.2 million of research funding to support our ophthalmology research program from the NHMRC and other Ophthalmology funding bodies. Each research project has been carefully managed to ensure that the project objectives are completed, that the budget considerations are reviewed on a monthly basis and that the research timelines are met. Each research project has a dedicated cost centre and the School's financial manager provides monthly audits of each cost centre for review. A fully audited report will be provided if required.

## 2.8 Budget

Resource (itemised)	2007-08	2008-09	2009 - 10	Total funds required
<b>Staffing costs</b> (GST Exclusive)				
1.0 FTE Lecturer ALB1		\$91,484		\$91,484
<b>Administrative costs</b> (GST Exclusive)				
Travel		\$4,545		\$4,545
Misc		\$7,782		\$7,782
Infrastructure (compulsory university research cost)		\$31,536.30		\$31,536.30
<b>Asset costs</b> (GST Exclusive)				
Computer/printer X 10		\$13 637		\$13 637
<b>TOTAL</b> <b>EHDGP funding</b> (GST Exclusive)		\$148,984		\$148,984
<b>TOTAL</b> <b>other funding sources</b> (GST Exclusive)				
10% GST		\$14,898		\$14,898
<b>TOTAL PROJECT COST</b> (GST Inclusive)		\$163,883		\$163,883

## 2.9 Organisational support

The project is supported by a strong HSR programme at the UWA and Curtin University. The HSR programme is regarded as a leader in its field, a major focus of which has been the development of the WA Safety and Quality of Surgical Care Project that includes a program of ophthalmology research. This has been supported by around \$1.2 million of research funding from the NHMRC and private industry. The research output of the HSR includes 160 scientific papers and has been presented at 240 local, national and international conferences. We have contributed to the provision of long-term research grants of around \$18.5million, which includes 18 NHMRC grants, one international grant, project grants from the State Health Department and funding from a diverse range of industry-based sources.

The HSR programme is fully supported by the research infrastructure within the School of Population Health at the UWA, The School of Public Health at Curtin University, as well as an extensive network of health/hospital based collaborators. We also have extensive experience in establishing clinical information systems to support operational audit and research. The HSR team will provide biostatistical support for data analysis, computer programming and database management advice, as well as a team of ophthalmologists to support this project.

## 2.10 Monitoring

We have extensive experience with managing numerous projects and the budgets associated with these. As we have done with our previous projects, we will discuss project progress and budget will through regular group meetings. These meetings will involve the project coordinator, the main investigators as well as representatives from each of the pilot hospitals and will have the specific purpose of assessing project progress and identifying and working through issues early to avoid project delays. We have well developed processes within our group to ensure projects progress within budget. As with all our projects, detailed financial records will be kept for this project and will be reviewed on a monthly basis to ensure the project continues within budget. Furthermore, the projects finances will be subject to a monthly audit by an external financial manager within the School of Population Health at the UWA.

## 2.11 Evaluation

A monthly meeting of the project team will ensure that direction and progress of the project is being achieved according to the project application. The project team will include Preen, Morlet and Semmens, the employed staff, as well as other ophthalmologists currently carrying out research within the HSR programme. This team will be review the project, ensure the resources that are required to meet the stated objectives are provided, and discuss/review any matters arising.

### Implement a web-based registry of cataract surgery in a cross section of WA hospitals:

Success will be determined by the number of sites with a successfully implemented theatre computer data entry system. This may require modifications to the software, and improved data entry protocols, to meet the needs of the individual hospital and surgeons. Surgeon acceptance will be a primary outcome.

### Use this cataract surgery registry to collect prospective data on cataract surgery procedures performed in WA:

The validity and completeness of the individual case data entry will be checked in a random sample by cross-checking with other sources and case-note reviews. Like-wise the completeness of data entry for all cataract cases will be assessed by random sampling and crosschecking with other theatre records.

**Determine the usefulness of the registry in assessing selected outcomes of cataract surgery in a cross-section of WA hospitals with a pilot study:** Using a selected outcome and a sample from the registry, an audit using case-note review and other cross-checking will highlight the benefits and any deficiencies of the system implemented.



ASSESSMENT CRITERION 4 - SUSTAINABILITY.

2.12 Sustainability

The successful completion of a pilot phase of the project will place us in a position whereby we can engage with other funding bodies, and the state health department to implement the cataract registry system state-wide. Demonstration of the usefulness of the system to all parties will engender future support. Once implemented, it is envisioned the registry we be an ongoing system.

Part Three - Agreements

3.1 If my application is successful I agree that a description of the project, amount of funding and organisation may be:

- used in media releases and other publications;
- provided to organisations or individuals with a view to them contacting me for further information; and
- used to compile a consolidated report.

YES

3.2 I understand that in the event that this application for funding is successful, I may be required to produce proof that the organisation making this application has sufficient insurance cover to conduct the proposed activities specified in this application form.

YES

3.3 I understand that by submitting this application, the organisation making the application is agreeing to abide by the terms of the Standard Funding Agreement with the Commonwealth, represented by the Department of Health and Ageing.

YES

## Part Four- Declaration

Please note that this Declaration should be signed by a representative of the Lead Organisation specified at Question 1.1 of this Application Form. Note that:

- A person who is legally empowered to give assurances and enter into contracts and commitments on behalf of your organisation should sign this application.
- Any application that does not provide all required information or contains false or misleading information will be excluded from consideration.

I hereby apply for a grant under the Eye Health Demonstration Grants Program – Funding Round Two of \$ 148,984

for **Monitoring cataract surgery outcomes in Western Australia: establishing a State-wide cataract surgery registry**

I certify that the information given in this application is complete and correct.

Signature: \_\_\_\_\_

Name (BLOCK LETTERS): \_\_\_\_\_

Position in Organisation: \_\_\_\_\_

Date: \_\_\_\_\_

## Referee Template – First reference

### ATTACHMENT A

Name: Prof Ian Constable Position: Director Centre for Ophthalmology and Visual Science  
 Organisation: University of Western Australia  
 Relationship to lead organisation: Nil  
 Length of time of relationship to lead organisation: N/A  
 Contact phone: Contact fax:  
 Contact Email: iconstable@cyllene.uwa.edu.au Contact mobile: YES

Are you available to be contacted for further information? YES  
**Question 1: Are you confident that the applicant is capable of completing this project within the desired budget and timeframe?**

**Comments:**

**The methodology is similar to a previous project on Endophthalmitis that the PI's completed. The risk is in getting the surgeons to complete the data entries fully. The time and budget are sufficient.**

**Question 2: Are you aware of any other eye health care or similar projects that this organisation has undertaken? If so, have they delivered satisfactory outcomes in line with their objectives?**

**Comments:**

**The WA endophthalmitis project was well executed and produced useful results.**

**Question 3: How is the applicant viewed by their peers (other research institutions, health care professionals, service providers, people with eye disease or low vision and their carers and families)? Please give examples if appropriate.**

**Comments:**

**I think the applicants are held in good standing by each of the listed stakeholders.**

**Additional Comments (if any): If a standard methodology for reporting results is developed, then it may have broad national applicability**

*Prof. Constable*

Signed: \_\_\_\_\_

Date 25 October 2007

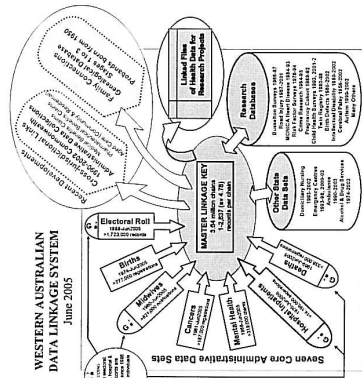


## Appendix B: The Western Australian Data Linkage System (WADLS)

The WADLS was established in 1995 as a complex, multi-set system for the creation, storage, update and retrieval of links between health-related data. It uses computerised probabilistic matching to create a dynamic master linkage key between over 30 population-based administrative and research health data collections in WA (population 2.0 million).<sup>1</sup> The linkages mean that the total historical population (3.7 million individuals going back as far as 1966) can be researched for all major diseases, their risk and protective factors and the utilisation and outcomes of health services. The WA Data Linkage Unit, located in Perth, builds the system on a foundation of seven core statutory elements: birth and death registrations, hospital separations (public and private), midwives' notifications of confinements, cancer notifications, mental health service encounters and State electoral roll registrations.

### WADLS applications and analytic methods development

The linkages within and between the health databases have created an information system not only rich in detail and comprehensive in scope, but also connecting in chronological order the important health events for each member of the WA population for the past three decades. The WADLS has supported over 350 distinct studies of disease aetiology, clinical needs analysis, patterns and costs of care and the outcomes of health services. It is accessible to any *bona fide* researcher who obtains ethics clearance and has at least one research collaborator in WA. Journal papers based on linked data from the WADLS number more than 300. The WADLS supports a successful Safety and Quality of Surgical Care Program established in collaboration with the College of Surgeons.<sup>2</sup> Specific methodologic developments include the backcasting model to correct for prevalent pool artefact in first-time incidence rates based on linked multi-event data,<sup>3</sup> the use of case distribution designs to estimate effects of index procedures and health events on short-term readmission risks,<sup>4</sup> and the development of an improved method of adjustment for confounding by comorbidity, the Multipurpose Australian Comorbidity Scoring System (MACSS).<sup>5,6</sup>



- Holman CD, Bass AJ, Rouse IL, Hobbs MS. Population-based linkage of health records in Western Australia: development of a health services research linked database. *Aust N Z J Public Health* 1999;23(3):453-9.
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- Brameld KJ, Holman CD, Lawrence DM, Hobbs MS. Improved methods for estimating incidence from linked hospital morbidity data. *Int J Epidemiol* 2003;32(4):617-24.
- Brameld KJ, Holman CD. Estimation of excess risk of readmission to hospital after an index inpatient separation. *Med Care* 2003;41(5):693-7.
- Holman CD, Preen DB, Baynham NJ, Finn JC, Semmens JB. A multipurpose comorbidity scoring system performed better than the Charlson index. *J Clin Epidemiol* 2005;58(10):1006-14.
- Preen DB, Holman CD, Lawrence DM, Baynham NJ, Semmens JB. Hospital chart review provided more accurate comorbidity information than data from a general practitioner survey or an administrative database. *J Clin Epidemiol* 2004;57(12):1295-304.

25 October 2007

Julie Hausstead

Eye Health Demonstration Grants Program Funding Round 2 (NEHI/02)

Department of Health and Ageing

Private Mail Box 2088

WODEN ACT 2606

Dear Ms Hausstead

### RE: APPLICATION FOR FUNDING UNDER THE EYE HEALTH DEMONSTRATION GRANTS PROGRAM FUNDING ROUND 2 (NEHI/02) – PREN/SEMMEIS

The Health Services Research Group (HSR) at Curtin University of Technology will work closely with the lead organisation (The UWA Centre for Health Services Research (CHSR)) to jointly support the project "Monitoring cataract surgery outcomes in Western Australia: establishing a State-wide cataract surgery registry" which aims to pilot the implementation of a cataract surgery registry in a cross-section of hospitals in Western Australia.

We have enjoyed a close collaborative arrangement with the CHSR at the UWA since moving to Curtin University this year and will continue to do so in this project. Our strong track record in ophthalmic research (we are the principle group behind the WA Safety and Quality of Surgical Care Project and the ophthalmic research component of this) and the group of ophthalmologists who form part of the HSR group at Curtin will contribute the clinical expertise necessary for the CHSR to successfully complete the project.

The nominated project officer who will oversee the project will be employed through Curtin University. Funding will be distributed to our organisation to cover this cost (as outlined in the budget provided).

Please be advised that our nominated contact officer is:

Professor James Semmens  
Director, Health Services Research  
School of Public Health  
Curtin University of Technology  
GPO Box U1987  
Perth WA 6845  
Tel: 08 9266 1856  
Fax: 08 9266 1866  
Email: [james.semmens@curtin.edu.au](mailto:james.semmens@curtin.edu.au)

Yours sincerely

Tony Tate  
Director, Research and Development

## **Appendix 5: Survey of Ophthalmology manuscript**

## "BIG DATA" IN OPHTHALMIC RESEARCH

Anthony Clark MBBS (Hons)<sup>1,2</sup>, Jonathon Q Ng PhD FRANZCO<sup>1,2</sup>, Nigel Morlet FRACS FRANZCO<sup>1,2</sup>,  
and James B Semmens MSc PhD<sup>1,2</sup>

<sup>1</sup>Centre for Population Health Research, Curtin University, Perth, Western Australia

<sup>2</sup>Eye and Vision Epidemiology Research (EVER) Group, Perth, Western Australia

**Word count:** 6,395

**Tables:** 3

**Figures:** 2

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"Big data" is a relatively new concept that describes data so large and complex that it exceeds the storage or computing capacity of most systems to process timely and accurate analyses.<sup>159,230</sup> Health generates huge amounts of data from a wide array of sources such as electronic health records (EHR), health insurance claims, and even smart phone applications that monitor patient health. It is the subject of intense interest as industry and researchers alike realize the huge potential in extracting value from existing data systems. The 'big data revolution' is being increasingly supported by national governments, who are funding initiatives designed to develop and capitalize on big data.<sup>57,159</sup> Even before the big data revolution, health researchers have long recognized the value in large administrative databases.<sup>252</sup> The last decade has seen a dramatic increase in the their use for ophthalmic research.<sup>33,215</sup> These databases contain a wealth of information that can now be accessed in a timely and cost-efficient manner due to advances in computing power and the development of new analytical methodologies required to analyze them.<sup>95</sup> These advances have also facilitated data integration processes that offer greater utility over using individual databases for health research e.g. linking pharmaceutical claims data to hospital discharge data allows study of health outcomes associated with medication use. It promises the potential for more, almost limitless, amounts of data available for research.

In this review we explore administrative databases used in ophthalmic research, how they compare with clinical registries, their benefits and limitations and outline some of the new developments for the future.

### ADMINISTRATIVE DATA AND CLINICAL REGISTRIES

Administrative databases used in health research are pre-existing datasets whose primary purpose is the storage of information routinely collected from the point of service, usually for billing purposes e.g. hospital insurance claims information and pharmaceutical billing data. The variables typically recorded range widely but generally include: a patient specific identification number, demographic details (e.g. name, sex, date of birth, and address) and limited clinical data (e.g. diagnostic/procedural codes in health insurance claims data or drug codes in pharmaceutical claims data). These databases are normally very

large, cover large defined populations within a given health jurisdiction, and span years if not decades of service (Table 1).

Clinical registries are different to administrative databases. They are designed to collate detailed and specific clinical information, usually for quality assurance and clinical audit. Only a few truly population-based ophthalmic registries currently exist, though this number is increasing e.g. cataract surgery,<sup>9,124</sup> and corneal transplant registries.<sup>29,38,168</sup> These registries are powerful tools for health research since they contain a level of detailed clinical information that current administrative databases simply cannot match.

### DATA INTEGRATION

Data integration (also known as data linkage) increases the utility of individual datasets by bringing together two or more different sources of data that relate to the same person, family or event.<sup>100</sup> Linking data for health research was first described by Dr. Halbert Dunn in 1946 when he proposed the concept of a 'book of life', its pages the records from significant events in a person's life e.g. birth, education, marriage, health and death (Figure 1).<sup>46</sup> Linkage requires identifiers common to all datasets.<sup>79,204</sup> These may be unique (e.g. a patient's insurance number), or partial (e.g. name, date of birth, gender, place of birth, postcode etc.) and are traditionally matched using three general techniques (Table 2). Most systems today use probabilistic matching techniques because even unique identifiers (e.g. social security number) can be inaccurate due to errors in recording.<sup>79</sup>

Linkage need not be confined to health-related datasets and indeed any dataset with the appropriate identifiers can be integrated. The opportunity for ophthalmic research is therefore limited only by the data available e.g. linking health and meteorological data allows disease trends across weather patterns to be studied,<sup>144</sup> or linking cataract operation data with road traffic data allows its impact on driving performance to be examined.<sup>162</sup>

Recognition of the immense value of data integration in supporting health research has led to a significant expansion in data linkage capacity and infrastructure across the globe with successful systems well established in Canada, Australia, the UK and the US.<sup>105,205</sup>

### BENEFITS AND LIMITATIONS OF BIG DATA AND DATA INTEGRATION

There has been some skepticism regarding the value of research arising from administrative data since it is observational by nature and these databases were never intended for use in health research.<sup>15,28</sup> This is compounded by the heavy emphasis on randomized controlled trials (RCT) as the 'gold standard' for evaluating treatment, which ignores the limitations inherent in RCT methodology. RCTs do not reflect real-life community practice, leaving clinicians to use their judgment in extrapolating findings from trials that relate to a highly selected patient that may be seldom encountered. Observational studies using large databases can complement RCTs by going some way towards addressing their limitations.<sup>15</sup> Their large size provides whole-population capture; thereby avoiding non-representative samples and selection bias, which may occur in randomized trials. They measure the true effectiveness of an intervention that is based on actual 'real world' practice which is highly variable unlike the highly controlled environment in RCTs. Whole population or big observational studies are also better powered to study rare events and small effect sizes due to very large sample sizes, and the typically long time span covered by many databases enables long-term events to be examined. Recall bias and bias related to non-participation and loss to follow-up is minimized since all eligible people are included. Because these databases are primarily created for administrative purposes then individual patient consent is usually not required or warranted.<sup>100,226</sup>

The advantages and social benefits of research arising from large administrative data and data linkage systems over traditional research methods are significant and include:

- i. decreased cost of research: using existing data is a relatively cheap and effective alternative to performing *de novo* studies,<sup>204,226</sup>
- ii. increased efficiency of research: access to existing clinical information vastly reduces the time needed compared to studies requiring primary data collection. This is particularly important when assessing safety of new treatments such as post-marketing surveillance of new drugs.<sup>20</sup>
- iii. conservation of patient privacy: the privacy of individual patients is conserved since it is usually not necessary for personal identifiers to

be provided to researchers.<sup>259</sup> Using large administrative databases also conserves privacy of all patients, regardless of whether they would have given consent to the use of their information. A consent-based approach conserves the privacy only of those who do not participate, usually at a cost of making the research irreconcilably impractical.<sup>99</sup>

- iv. adding value to existing information assets: integrating datasets is a non-invasive and cost-effective means to generate a greater return on the substantial existing investment in routine administrative data sets.<sup>197</sup> It also adds value to existing data sets through assisting in quality improvement of data through the linkage process.

Limitations of studies that use administrative data surround the use of data whose primary purpose is not for research.<sup>33,104,215</sup> The researcher should be cognizant of how the data was collected and coded. The first hurdle relies on the patient with a particular condition seeking care – if it is not serious enough to warrant seeking health care it will not be recorded and cannot be studied. There also needs to be a code attached to the condition or procedure of interest (usually International Classification of Diseases codes (ICD) e.g.; ICD-10<sup>175</sup> so any additional non-coded clinical data cannot be studied. Codes may not be specific enough to allow more detailed study (e.g. ‘glaucoma’ rather than ‘pigment dispersion glaucoma’) and may not necessarily indicate the severity of a condition. Establishing laterality to a particular eye is a major problem since many datasets historically did not record this information and may limit investigation of adverse events.

Data quality and completeness will tend to vary across databases and variables being studied. Some errors are less likely to occur e.g. coding for primary surgical procedures; while others have been shown to be prevalent e.g. omitted coding for secondary diagnoses.<sup>104,206,215</sup> Databases may also change over time with changes in codes and the addition or deletion of variables. The way data is generated or collated may also vary between datasets and with time.<sup>104</sup> It is essential that the researcher intimately understand how their data was generated and how it may have evolved over time. A close working relationship between researcher and data custodian is essential if errors in analysis and

interpretation are to be avoided. Validation studies with chart review may be required to help quantify the size of these issues within any given data collection.<sup>8,77,143,192,254</sup>

Care must also be taken when calculating incidence/prevalence or generalizing results to the wider population since many databases contain a limited subset of the population that is unlikely to be representative of the whole. For example, the US Medicare database only includes those who are older than 65 years, disabled, or poor; while private health insurance company claims data is limited to those who can afford health insurance and omits the more vulnerable lower socioeconomic groups and racial minorities without insurance who are more likely to need care. The limited coverage of insurance databases also means loss to follow-up can be an issue when patients move in and out of the insurance organization. Conversely databases in jurisdictions with universal health care, and particularly data linkage systems, are truly population-based and so are readily generalized with very little loss to follow-up that can offer true measures of incidence and prevalence. For example, linking cancer registry data with data from a local cancer referral center in Germany increased the incidence of uveal melanoma by nearly four times compared to using cancer registry data alone (from 2.3 to 8.6 cases per million PY).<sup>234</sup>

Finally, analysis of these databases should take into account the risk of confounding due to comorbidity, socio-demographic factors and effect modification.<sup>33,215</sup> Multivariate modeling and other techniques can be used to adjust for these effects so long as they are present in the data. If these limitations are addressed in the study design, data analysis and interpretation; then any study findings using administrative data can still provide valuable additional information to the available evidence.

## APPLICATIONS IN OPHTHALMIC RESEARCH

Large administrative databases have been used in a broad range of ophthalmic research studies into disease surveillance, disease etiology, health service utilization and health outcomes (including post-marketing surveillance).

### DISEASE SURVEILLANCE

Data on prevalent or incident events is required to understand patterns of



disease in the community and may be readily available in health administrative databases (with the caveats already outlined). Large datasets are particularly useful in the study of rare diseases due to the sheer size of the population they cover; and since many span decades, they are also ideal for studying the longitudinal patterns of disease. For example, the incidence of primary angle closure glaucoma (PACG) was first described by Erie et al in 1997 using hospital administrative data from the Rochester Epidemiology Project (REP); they reported an annual incidence of 8.3 per 100,000 (95% CI, 5.6-11.0) in the over 40 year olds in Olmstead County, Minnesota for 1980-1992.<sup>51</sup> A similar study using hospital admission data in Singapore by Wong et al in 2000 found the annual incidence of PACG in an Asian population was higher at 11.1 per 100,000 (95% CI, 10.4-11.8).<sup>270</sup> Hu et al used whole-population health insurance claims data from 503,687 people in Taiwan to describe the relationship between cataract surgery and admission for acute angle closure over the eight-year period 1997-2004. They found a significant correlation between the decline in acute angle closure and the rise in cataract surgery (Spearman rank  $r = -0.407$ ,  $P < 0.001$ ).<sup>102</sup> Other studies have examined the incidence and/or prevalence of vision loss and blindness,<sup>40</sup> glaucoma,<sup>25,140,229,241,255</sup> diabetic retinopathy,<sup>139,229</sup> age-related macular degeneration (ARMD),<sup>121,139</sup> co-morbidity with ARMD,<sup>271,275</sup> retinal detachment,<sup>52,167,269</sup> sixth nerve palsy,<sup>187</sup> strabismus,<sup>161</sup> dry-eye disease,<sup>272</sup> retinopathy of prematurity,<sup>78</sup> ocular trauma,<sup>26,27,268</sup> retinal vein occlusion,<sup>96</sup> endophthalmitis,<sup>26,103,129,171,231,266</sup> and spinal surgery-related posterior ischemic optic neuropathy.<sup>189</sup>

#### DISEASE ETIOLOGY

While it is not possible to establish causality in retrospective observational studies, administrative database studies can assist in identifying potential factors in the etiology of ocular disease to direct further study in a time and cost efficient manner. This is particularly useful in the study of rare diseases when large numbers are required to establish any meaningful associations. Vajdic et al used data from the Australian nationwide kidney dialysis and transplant registry, linked with the cancer registry, to generate a cohort large enough to study the association between immunosuppression and the rare disease ocular squamous

cell carcinoma (SCC). The study included 10,180 renal transplant patients over 86,898 person-years follow-up and found a 20-fold increase in the incidence rate of ocular OSCC in immunosuppressed patients (standardized incidence ratio 19.5, 95% CI 6.3-45.5).<sup>260</sup> They were the first to report on the association outside of the known link with human immunodeficiency virus and added further weight to the hypothesis that immunodeficiency has a role in ocular SCC. In another more recent study, Bonamy et al reported findings from their population-based study using linked population registries examining the risk of late retinal detachment in preterm infants born in Sweden.<sup>18</sup> This large study of over 3 million births spanned 35 years since 1973 with a median follow-up of 17.4 years. Retinal detachments after preterm birth are rare with just 0.029 cases per 1000 person-years. Significant risk factors were birth before 32 weeks and male gender. The risk (HR) of retinal detachment for extremely preterm infants (<28 weeks) and preterm infants (28-31 weeks) was 19.2 and 4.32 respectively for infants born 1973-1986; which decreased to 8.95 and 2.80 respectively for infants born 1987-2008 after the introduction of routine retinopathy of prematurity screening. Males were nearly twice as likely to have a late retinal detachment.

Other examples include a study on the association between reduced sunshine exposure and increased angle closure glaucoma;<sup>256</sup> genetics and open angle glaucoma;<sup>253</sup> diabetes and an increased risk of glaucoma,<sup>48</sup> sixth nerve palsy,<sup>187,188</sup> and acute conjunctivitis;<sup>137</sup> risk factors for central retinal vein occlusion;<sup>245</sup> and the lack of association between vitamin D deficiency and macular degeneration.<sup>44</sup>

#### HEALTH SERVICES UTILIZATION

Understanding patterns and trends in eye service use is essential to adequate planning by governments and agencies to anticipate service needs and costs. This is particularly important for appreciating variations in the patterns of care between clinical sub-populations (e.g. sociodemographic and geographic groups) for identifying areas of service deficiency or inefficiency. Large health administrative databases are ideal for studies on health service utilization since they are derived from the delivery of these services meaning

every clinical service encounter is ‘captured’ to provide an entire-population cohort on which to conduct research without the need to extrapolate findings. The richness of information on service provision contained in these databases is reflected in the volume of ophthalmic research published in this area. The majority of studies have examined trends and patterns of ophthalmic services use over time, and across socio-demographic and geographic groups. Many of these focused on trends in eye surgery and use of ophthalmic drugs (particularly for glaucoma).

#### Patterns of care

Establishing trends in ophthalmic service use over time is easily achieved using administrative databases since most span decades. The first data linkage study to examine trends in ophthalmic services was the Oxford Record Linkage Study, in the Oxford region of the UK in 1991.<sup>59</sup> The study found the use of ophthalmic services increased 16.3% over an 11-year period (1975-1985), while the length of stay per admission to hospital decreased from 6.5 to 4.8 days. Subsequently Ellwein et al analyzed data from the US Medicare database of over 65 year olds to look at trends in eye care utilization and the type of providers providing this service.<sup>49,50</sup> They found a 6.7% rise (41.4% to 48.1%) in the proportion of people accessing eye services between 1991 and 1998; and that ophthalmologists provided the majority of eye care billed under Medicare (71%).

Identifying areas of under and over servicing is important in the equitable distribution of limited health resources particularly to vulnerable populations. Such patterns of service delivery are readily identified using health administrative databases that cover large population cohorts across geographic and demographic boundaries. This allows patterns of service delivery across socioeconomic, race, gender, and geographic groups to be examined. In Western Australia linked whole-population hospital administrative data was used to describe the growing inequity in the cataract surgery rate for rural/remote (metropolitan patients had 24% more surgery) and lower socioeconomic groups (the disadvantaged had 9% less surgery), despite an overall improvement in access to cataract surgery.<sup>176,178,261</sup> Other studies have found similar socioeconomic and geographic variations in cataract surgery utilization in the UK using the Oxford record linkage study (ORLS)<sup>130</sup> and in the US using Medicare

data.<sup>55,118,210</sup>

Racial variation in the treatment of glaucoma was reported in several US studies using Medicare/Medicaid data. Most found the rates of eye service use in African-Americans were as much as 50% lower than Caucasians despite an increased prevalence of glaucoma in the African-American population.<sup>45,80,113,184,264</sup>

In Western Australia, linkage of blind register data with whole-population hospital data allowed health utilization by the severely vision impaired to be studied for the first time. Significantly more hospital attendances for blind adults (incidence rate ratio [IRR] 1.5, 95%CI 1.1-2.0) and children (IRR 4.2, 95%CI 1.9-9.3) was found compared to those who had no vision loss.<sup>41,42</sup> Other examples of studies of patterns of eye service utilization in specific populations include those in women,<sup>91</sup> children,<sup>133</sup> and diabetics.<sup>201,220</sup>

#### Trends in surgery

Surgical trends are particularly suited to study using large administrative databases since such encounters are almost universally recorded. Cataract surgery rates have increased dramatically in studies from most Western countries since the adoption of phacoemulsification, with most reporting a doubling in rates every 10 years (Figure 2a)<sup>7,53,67,84,92,10,219</sup> that are projected to increase further.<sup>94</sup> Conversely the introduction of prostaglandin analogues and increased uptake of laser trabeculoplasty<sup>111</sup> has seen the rate of glaucoma filtering surgery decline significantly by between 29 and 75% over a 10-year period since the mid-1990s (Figure 2b).<sup>21,131,185,195,250</sup> Retinal procedures have also changed significantly in the US medicare population between 1997 and 2007, particularly an explosion in intravitreal injections (<5000 procedures in 1997 to 812,413 procedures in 2007); a 72% increase in vitrectomy and a 69% decrease in scleral buckle only surgery; and an 86% increase in pan retinal photocoagulation procedures.<sup>196</sup>

#### Pharmacoepidemiology

Patient compliance with prescribed treatment in chronic diseases such as glaucoma is notoriously poor.<sup>217</sup> Pharmaceutical claims and health insurance databases have been used extensively in the US to study general trends and patterns in eye drop utilization and the factors affecting their use.<sup>39,75,123,235,236</sup>

Claims data has the advantage over other research methods since they avoid recall bias, which can be problematic in studies that rely on self-reporting. Patient adherence and persistence with their glaucoma medication provides an insight into compliance and also the effectiveness and tolerability associated with a particular drug or class of drug. Reardon et al used health and pharmaceutical claims data from the Protocare Sciences managed care database to study over 28,000 patients aged over 20 years who were dispensed topical ocular hypotensives.<sup>190,198,199,216</sup> They found that discontinuation rates were high; only 33% of those prescribed latanoprost were still using it after 12 months and continued use in other drug classes were even lower (19%). They also found latanoprost had less rates of discontinuation compared to all other glaucoma medications, including the other prostaglandin analogues. Similar findings were reported in later studies. Nordstrom et al found half of patients had discontinued treatment by 6 months and that those taking prostaglandins were 60% less likely to discontinue compared to beta-blockers and carbonic anhydrase inhibitors.<sup>180</sup> Other studies using claims data further support the findings from these studies,<sup>134,386,221,233,267,273,274</sup> including one from Australia using national population-based pharmaceutical claims for 357,099 patients that confirmed superior persistency for prostaglandins.<sup>194</sup> Pharmacoepidemiology studies using administrative data have their own unique limitations.<sup>215</sup> Caveats that should be considered when estimating patient compliance include: inaccuracies when a patient is given sample medications or their medication is obtained from outside their insurance plan; being unable to ascertain whether cessation of a prescription is due to a management decision by the patient's physician or a non-compliant patient; and that simply dispensing a prescription does not mean the patient is actually using the medication as prescribed. We also know from validation studies using chart review that for glaucoma, claims data alone tends to overestimate disease severity and is not able to correctly identify which patients are truly new to treatment.<sup>77,192,215</sup> The Glaucoma Adherence and Persistency Study attempted to address some of these limitations by using a combination of health insurance claims data and pharmacy claims data, validated with chart review and structured interview of patients and physicians.<sup>77</sup> Even taking these factors into account, adherence and persistency

rates were still poor. They found that only 10% of patients were continuously persistent with prescribed treatment over a 1 year period and at 1 year only 59% were adherent to any ocular hypotensive treatment.

### HEALTH OUTCOMES

In contrast to traditional clinical trials, health outcomes research examines clinical practice as it is actually performed in the community to answer questions about 'real world' effectiveness. Health administration databases, being born out of actual practice, are therefore particularly well placed for outcomes research. They also do not suffer from some of the limitations inherent in other traditional cohort, case-control and randomized controlled trials. Studies of health outcomes in ophthalmic research have generally focused on surgical safety, monitoring adherence to best practice, and post-marketing surveillance.

#### Surgical safety

Outside of the clinical trials, monitoring surgical safety typically relies on reporting adverse events through case series from single or multiple centers or clinics. Events identified in this way may be selective or incomplete. They also do not necessarily reflect the practice occurring in the wider community where there is likely significant variation in surgical case mix and complexity, surgeon experience, and quality of available equipment. While clinical registries may address most of these issues, administrative datasets are more likely to be complete and less easily 'gamed'.

The excellent safety profile of cataract surgery requires very large sample sizes over prolonged periods of time to identify and adequately study trends and risks of adverse events. Using Medicare data, Stein et al found just 0.5% of 220,000 cataract surgeries resulted in a serious adverse event over a 13-year period (1994-2006); and because of the large sample size they were able to report on a significant declining trend.<sup>240</sup> In Western Australia a similar study of 129,982 cataract procedures using whole-population hospital administrative data found 1.6% had a serious adverse event and there was a similar declining trend over a 22 years (1980-2001).<sup>30</sup> Bell et al found surgeon operative volume was important in the risk of adverse outcomes by pooling data from provincial health insurance claims data for over 230 surgeons and 284,797 cataract surgeries in

Ontario; surgeons performing over 1,000 cataract procedures per year had 0.1% adverse events compared to 0.8% in those performing 50-250 procedures (OR 0.14, 95%CI 0.09-0.23).<sup>11</sup>

A large sample size is particularly relevant to the study of rarer events e.g. endophthalmitis. Studies using health insurance claims and hospital administrative data showed the incidence of endophthalmitis ranged between 1 and 2 per 1,000 cataract surgeries.<sup>58,93,115,117,129,144,179,231</sup> Sample sizes in excess of 100,000 in these studies allowed identification of potential risk factors including increased risk in males, the elderly, complicated surgery, lower surgeon volume, and surgery in private facilities.<sup>58,93,115,117,129,144,179,231</sup>

Javitt et al used US medicare claims data to be the first to demonstrate a statistically significant increased risk of retinal detachment after intracapsular, extracapsular and phacoemulsification cataract surgery.<sup>114,117</sup> They found greatest risk of retinal detachment with intracapsular surgery (1.55%) and were the first to describe an increased risk with phacoemulsification compared to extracapsular surgery (1.17% vs 0.9%). They also found a statistically significant increased risk in males (RR 1.66), younger patients (RR 3.70 65-69 vs 80-89 yrs), whites (RR 3.85) and surgery where anterior vitrectomy was performed (RR 4.5). It was only through a large sample size that they were able to confirm these findings (which had previously been suspected but not confirmed due to limited sample sizes of previous studies). Other large database studies have since confirmed these findings.<sup>14,16,17,31,52,207,223</sup>

The combination of relatively uncommon procedures and rare complications further highlights the need for whole-population methodology and large sample sizes. Haargaard et al demonstrated this in their report of the long-term risk of retinal detachment after pediatric cataract surgery in Denmark 1977 – 2005.<sup>87</sup> Despite 28 years of data and 1,043 eyes (656 children) having pediatric cataract surgery, only 25 eyes (23 children) developed a retinal detachment. They demonstrated that 3% of children with isolated pediatric cataract will develop a retinal detachment within 20yrs of surgery. Significant risk factors were mental retardation (23%) and cataract plus other ocular or systemic pathology (16%). Importantly primary posterior capsulotomy and anterior vitrectomy did not increase the risk of retinal detachment.

One caveat of purely database studies is their limited ability to study a broad range of risk factors as they may not be coded, or the accuracy of coding for that risk is inconsistent e.g. smoking. Case-control methodologies using chart review for the cases and a random sample of the un-affected population may overcome this problem. For example the Endophthalmitis Population Study of Western Australia used population-wide hospital administrative data for an entire cataract surgery cohort of 117,083 over a 20-year period and 205 cases of endophthalmitis. Every case of endophthalmitis was validated with chart review and a nested case-control study was used to identify important surgical and non-surgical risk factors, including previously unreported associations with winter procedures (OR 1.48 95% CI 1.00–2.18) and concurrent eyelid surgery (OR 23.50, 95% CI 8.50–64.98).<sup>144,179</sup>

A similar nested case-control study examined risk factors for retinal detachment after cataract surgery in the Medicare population.<sup>116,257</sup> They found an increase risk with Nd:YAG capsulotomy (OR 3.8, 95% CI 2.4-5.9) along with other risk factors for retinal detachment that included: axial length, a history of lattice degeneration or retinal detachment or ocular trauma, and refractive error.<sup>257</sup> Other cataract surgery outcomes studied using linked data include the impact of cataract surgery on the increased risk of corneal oedema;<sup>24</sup> reduced vehicle crash risk (through linkage with road accident databases);<sup>162,164</sup> an increased risk of falls (through linkage with emergency room databases);<sup>163,165</sup> reduced admission for depression (through linkage to mental health services);<sup>166</sup> and reduced risk of death (by linking to death registers).<sup>71,248</sup>

Studies reporting outcomes for other surgical procedures are fewer in number and include adverse events after glaucoma-related procedures<sup>34,237,258</sup>, pars plana vitrectomy,<sup>238</sup> and penetrating keratoplasty.<sup>1</sup>

#### Monitoring adherence to best practice

Administrative datasets are being increasingly used to audit adherence by patients and physicians to 'best practice'. They are felt to offer a more accurate picture of real world practice since they are not affected by recall bias present in traditional surveys or clinical registries. Screening for diabetic retinopathy is particularly suited to such an approach due to well-established clinical guidelines and the ability to readily identify service encounters within most

administrative datasets. Reports from health claims databases suggest eye examination rates for diabetics are universally poor. Wang et al found only 53% of 175,015 diabetic Medicare beneficiaries had at least one eye care visit in a 1 year period, and only 67% within 2 years.<sup>263</sup> Similar proportions were reported using claims data elsewhere in the US.<sup>5,128,140,186,220,228</sup> While in Nova Scotia, Canada longitudinal claims data over 10 years indicated only 14.4% of diabetics had at least one eye examination consistently each year.<sup>136</sup> Factors consistently associated with less attendance are younger age, male gender, ethnic minorities, lower education level, and lower socioeconomic status.<sup>173,228,263</sup> Direct mail reminders to improve low attendance was studied but they were found to have only a short lived and modest effect at best.<sup>89,191</sup>

The practice patterns of physicians treating glaucoma has received some attention. Friedman et al found using health insurance data that 17% of glaucoma suspects and 16% diagnosed with glaucoma did not have a documented follow-up. They also found only half of these patients had at least one VF test within the follow-up period and just 13% had optic disc imaging (median follow-up 440 days).<sup>76</sup> Coleman et al found less than half of US medicare patients undergoing glaucoma surgery had gonioscopy performed in the preceding 4-5 years,<sup>36</sup> and just 70% had a field test in the preceding 1 year.<sup>35</sup> More recently Stein et al demonstrated a change in practice for glaucoma monitoring with use of visual field testing falling by 44% while the use of other ocular imaging modalities increased by 147% from 2001 to 2009.<sup>243</sup>

#### Post-marketing surveillance

Monitoring the safety of new drugs or medical devices following their widespread release into the community is an important part of health outcomes research. Approvals for their use are based on stringent testing in the setting of highly controlled clinical trials; but these trials are generally limited by small samples sizes of select populations that perhaps bear little resemblance to the wider clinical setting where the products are used. So post-marketing surveillance becomes essential to assess the safety of new medical products once released.

Information regarding medication safety is typically managed through national drug surveillance bodies e.g. the US Food and Drug Administration (FDA) agency.

Reporting adverse events to these bodies commonly relies on voluntary submission, which may be from multiple sources i.e. directly from the manufacturing company, the public, or independent organizations. The problem with this approach is it cannot provide useful population incidence rates since the population at risk is not quantified. There is also significant under-reporting and variability in the quality of reporting.<sup>203</sup>

Administrative databases are ideal to assist in post-marketing surveillance due to their large population cohorts allowing rare adverse events to be studied, ready access to current data, and relative cost effectiveness compared to traditional trials. The US FDA has recognized their value in several reports, and they recommended a greater use of population-based datasets to enhance post-marketing surveillance systems.<sup>23</sup>

There are a limited number of studies making use of administrative and linked datasets in post-marketing surveillance of ophthalmic drugs and devices despite them being ideal for this. French et al have published several studies using clinical and pharmacy data from the US Veterans Health Administration database that explored the association between drugs and eye disease. They found a temporal relationship between commencement of amantadine and the onset of corneal edema in a small proportion of patients (0.12%), which supported earlier case reports of the association.<sup>61</sup> They reported that 479,489 men using phosphodiesterase inhibitors had a small, but not significant, increased risk of anterior ischemic optic neuropathy;<sup>63,160</sup> and no association with central serous retinopathy.<sup>64</sup> They also found no association between the bisphosphonates and uveitis/scleritis (OR 1.23, 95% CI 0.85-1.79).<sup>62</sup> In another study they demonstrated an interesting reduced risk of death with any glaucoma medication (OR 0.93; 95% CI 0.90-0.95),<sup>66</sup> which confirmed findings from earlier large database studies.<sup>81,239</sup>

The safety of the anti-VEGF treatments for neovascular ARMD was recently studied. French et al found no difference in the risk of mortality for bevacizumab or ranibizumab (OR 0.89, 95% CI 0.74-1.06) in a cohort of 3,210 patients given intravitreal anti-VEGF and 117,364 unexposed ARMD patients.<sup>68</sup> This was supported by a Canadian study that used insurance claims data for 91,378 patients in Ontario.<sup>22</sup> While an Australian study found a small but significantly

increased risk of myocardial infarction (OR 2.3, 95% CI 1.2-4.5).<sup>132</sup>

Other examples include finding no risk of congestive heart failure with topical glaucoma medications;<sup>169</sup> inconsistent results about the reduction in Nd:YAG laser capsulotomy rates with the introduction of square edge intra-ocular lenses;<sup>32</sup> an increased risk of retinal detachment with oral fluoroquinolones;<sup>56</sup> and the apparent protective effect of statins in open angle glaucoma.<sup>242</sup>

#### HEALTH ECONOMICS

Determining the cost and demand for ophthalmic services is an important for health care planning, particularly in the climate of dwindling health budgets and rapidly increasing health care costs. Administrative data are particularly useful for estimating these costs since they are recorded at the point of service and usually contain billing information to calculate actual costs.

Examples are numerous, particularly studies using Medicare claims data.

Findings have included: cataract surgery cost USD\$2500 in 1991;<sup>244</sup> there was a 10-25% decrease in the cost of eye care to Medicare during the 1990s despite an increase in the proportion of beneficiaries receiving eye care (due to a reduction of cataract surgery payments);<sup>50,208</sup> physician reimbursement as fee for service is associated with approximately twice the rate and cost of cataract surgery compared to a cost capitation model;<sup>225</sup> fee cuts for ophthalmic surgery increased volume but had no effect on overall cost;<sup>120</sup> increasing surgeon supply increased access to surgeons but did not increase the demand for services by individual patients;<sup>54</sup> vision loss is associated with and extra USD\$2,193 to \$4,443 in health care costs or USD\$2.14 billion for the entire Medicare population in 2003;<sup>122</sup> introducing prostaglandins for glaucoma increased adherence without significantly increasing costs;<sup>13</sup> the cost of post-operative complications like endophthalmitis (US\$16,142 higher claims per case)<sup>211</sup> and cystoid macular edema (40-50% higher claims and payments).<sup>212</sup> Studies have also calculated the cost of providing specific ophthalmic medications (e.g. eye drops),<sup>60,106</sup> while others have quantified the significantly higher health expenditure associated with diabetic retinopathy,<sup>138,213</sup> and diabetic macular oedema;<sup>222</sup> ARMD;<sup>37,90</sup> and primary open angle glaucoma (USD \$242 to \$1,570).<sup>142,193,195</sup>

#### FUTURE ADVANCES

A major limitation in using administrative data for health research is the lack of robust clinical detail that precludes more detailed analysis beyond that of basic diagnostic and procedure codes. While nested case-control studies may offer some solution by allowing a manageable number of cases for chart review, it is at the cost of timely and efficient research.

Clinical registries offer another solution. An excellent example of a successful population-based ophthalmic clinical registry is the Swedish national cataract register (NCR). The NCR began in 1992 and now contains over 1 million cataract procedures representing 95.6% of cataract surgeries performed in Sweden.<sup>9</sup>

Detailed pre-, intra-, and post-operative clinical information has allowed in-depth analysis of cataract surgery trends and outcomes in particular.<sup>3,69,108,93,110,125,135,145-158,170,246,247,251,265</sup>

Like many clinical registers, the data contained in the NCR are submitted by participating center via a form for each cataract procedure. This method is potentially subject to error from data entry and transposition when copying data from the medical record and from the form onto the database.<sup>88</sup> It is also duplication of data entry.

If physicians are to be encouraged to contribute to clinical registries then the process should be a seamless integration that doesn't disrupt physician workflow. Ideally data would be transferred directly from the clinical record into the clinical registry database without the need for duplication of data entry. Improvements will come with automated data collection methods and new analytic techniques.

#### Automated data extraction and collection

Purpose built clinical registries aggregated by scraping data from electronic health records (EHR) offers a practical and efficient solution. This was demonstrated in the UK in the national cataract database which collated data from EHR across 12 NHS trusts for 55,567 cataract operations between 2001 and 2006.<sup>12,47,124,126,134,174,232</sup> This projected laid the groundwork that has subsequently been extended to a national ophthalmology database.<sup>107-109</sup> Although only 40% of ophthalmic practices in the USA use an EHR the American

Academy of Ophthalmology's newly commissioned IRIS Registry (Intelligent Research in Sight) offers the promise of a national comprehensive eye disease register. It is designed to assist in delivering quality patient care through measuring and reporting outcomes and bench-marking.<sup>4</sup> A breakthrough in the design of the registry was its integration with physician EHR that avoids disruption of physician workflow and duplicate data entry that are major barriers to the implementation and ongoing success of clinical registries.<sup>4</sup> Despite the current political imperative, improving the design and ergonomics of EHR's will be required to expand their use throughout the wider ophthalmic community. However as a stand-alone database, IRIS will provide significant insights into ophthalmic disease and clinical practice on an individual and population level.

Methods are required to utilize the existing information held electronically as text files, as there is a huge amount of legacy data stored since the advent of word-processors. That information would provide further important historical data to assess trends in diagnosis and management. Such techniques may also enable integration of written reports from other areas such as pathology and radiology.

There is also the potential to support a vast program of ophthalmic research through data integration processes into areas that determine social and economic determinants of health such as educational and welfare records. The impact of ophthalmic disease on other health outcomes e.g. injury and mental health may be usefully assessed with data integration.

As more data sources are created and data integration process allows the linkage of multiple data sources, then the volume of data available for research will continue to grow. This begs the question - how do you then deal with such massive amounts of data? Big data methodologies being developed allow the efficient study of large databases using machine learning algorithms that offer the promise of better predictive models, the ability to deal with non-validated 'dirty' data without the need for comprehensive data cleaning, and faster computing with more data.<sup>127</sup>

## SUMMARY

Large administrative and linked databases are readily available and rich sources of information for ophthalmic research. Much use has already been made of them with a trend towards increasing output as researchers realize their value in addressing a wide range of research questions, particularly relating to ophthalmic service utilization and outcomes. Their value in post-marketing surveillance of new drugs and devices is particularly worth noting. Administrative datasets are not without their limitations but many of them can be overcome with appropriate study design, analysis and careful interpretation. The development of clinical registries and big data analysis techniques is a promising trend that has the potential to allow more rapid analysis without the need for extensive data validation. Their benefits in providing a 'real world' view of ophthalmic disease, services and outcomes in a timely fashion that conserves the health dollar should not under-estimated.

## METHOD OF LITERATURE SEARCH

A PubMed and Web of Science search was performed for the terms "administrative data", "medicare", "claims data", "data linkage", "record linkage", "insurance data", "pharmaceutical data", "post-marketing surveillance", "registry", and "register" in various combinations with ophthalmic related terms "ophthalmology", "eye", "vision", "glaucoma", "macular degeneration", "cataract", "blind", "diabetic retinopathy", and "optic" across all years. A review of the abstracts identified relevant articles, which were confirmed after reading. The citations from these articles were also used to identify articles not found with the above search terms. Any non-English references were excluded.

Table 1 – Administrative databases and data linkage systems most commonly used for ophthalmic research		
Dataset	Country	Description
<b>Medicare</b> <sup>1, 5, 6, 8, 13, 19, 24, 26, 30, 34, 37, 41, 46, 49, 50, 54, 55, 56, 60, 63, 68, 69, 71, 74, 111, 113, 121, 126, 128, 130, 131, 132, 133, 134, 135, 136, 137, 138, 139, 140, 141, 142, 143, 144, 145, 146, 147, 148, 149, 150, 151, 152, 153, 154, 155, 156, 157, 158, 159, 160, 161, 162, 163, 164, 165, 166, 167, 168, 169, 170, 171, 172, 173, 174, 175, 176, 177, 178, 179, 180, 181, 182, 183, 184, 185, 186, 187, 188, 189, 190, 191, 192, 193, 194, 195, 196, 197, 198, 199, 200, 201, 202, 203, 204, 205, 206, 207, 208, 209, 210, 211, 212, 213, 214, 215, 216, 217, 218, 219, 220, 221, 222, 223, 224, 225, 226, 227, 228, 229, 230, 231, 232, 233, 234, 235, 236, 237, 238, 239, 240, 241, 242, 243, 244, 245, 246, 247, 248, 249, 250, 251, 252, 253, 254, 255, 256, 257, 258, 259, 260, 261, 262, 263, 264, 265, 266, 267, 268, 269, 270, 271, 272, 273, 274, 275, 276, 277, 278, 279, 280, 281, 282, 283, 284, 285, 286, 287, 288, 289, 290, 291, 292, 293, 294, 295, 296, 297, 298, 299, 300, 301, 302, 303, 304, 305, 306, 307, 308, 309, 310, 311, 312, 313, 314, 315, 316, 317, 318, 319, 320, 321, 322, 323, 324, 325, 326, 327, 328, 329, 330, 331, 332, 333, 334, 335, 336, 337, 338, 339, 340, 341, 342, 343, 344, 345, 346, 347, 348, 349, 350, 351, 352, 353, 354, 355, 356, 357, 358, 359, 360, 361, 362, 363, 364, 365, 366, 367, 368, 369, 370, 371, 372, 373, 374, 375, 376, 377, 378, 379, 380, 381, 382, 383, 384, 385, 386, 387, 388, 389, 390, 391, 392, 393, 394, 395, 396, 397, 398, 399, 400, 401, 402, 403, 404, 405, 406, 407, 408, 409, 410, 411, 412, 413, 414, 415, 416, 417, 418, 419, 420, 421, 422, 423, 424, 425, 426, 427, 428, 429, 430, 431, 432, 433, 434, 435, 436, 437, 438, 439, 440, 441, 442, 443, 444, 445, 446, 447, 448, 449, 450, 451, 452, 453, 454, 455, 456, 457, 458, 459, 460, 461, 462, 463, 464, 465, 466, 467, 468, 469, 470, 471, 472, 473, 474, 475, 476, 477, 478, 479, 480, 481, 482, 483, 484, 485, 486, 487, 488, 489, 490, 491, 492, 493, 494, 495, 496, 497, 498, 499, 500, 501, 502, 503, 504, 505, 506, 507, 508, 509, 510, 511, 512, 513, 514, 515, 516, 517, 518, 519, 520, 521, 522, 523, 524, 525, 526, 527, 528, 529, 530, 531, 532, 533, 534, 535, 536, 537, 538, 539, 540, 541, 542, 543, 544, 545, 546, 547, 548, 549, 550, 551, 552, 553, 554, 555, 556, 557, 558, 559, 560, 561, 562, 563, 564, 565, 566, 567, 568, 569, 570, 571, 572, 573, 574, 575, 576, 577, 578, 579, 580, 581, 582, 583, 584, 585, 586, 587, 588, 589, 590, 591, 592, 593, 594, 595, 596, 597, 598, 599, 600, 601, 602, 603, 604, 605, 606, 607, 608, 609, 610, 611, 612, 613, 614, 615, 616, 617, 618, 619, 620, 621, 622, 623, 624, 625, 626, 627, 628, 629, 630, 631, 632, 633, 634, 635, 636, 637, 638, 639, 640, 641, 642, 643, 644, 645, 646, 647, 648, 649, 650, 651, 652, 653, 654, 655, 656, 657, 658, 659, 660, 661, 662, 663, 664, 665, 666, 667, 668, 669, 670, 671, 672, 673, 674, 675, 676, 677, 678, 679, 680, 681, 682, 683, 684, 685, 686, 687, 688, 689, 690, 691, 692, 693, 694, 695, 696, 697, 698, 699, 700, 701, 702, 703, 704, 705, 706, 707, 708, 709, 710, 711, 712, 713, 714, 715, 716, 717, 718, 719, 720, 721, 722, 723, 724, 725, 726, 727, 728, 729, 730, 731, 732, 733, 734, 735, 736, 737, 738, 739, 740, 741, 742, 743, 744, 745, 746, 747, 748, 749, 750, 751, 752, 753, 754, 755, 756, 757, 758, 759, 760, 761, 762, 763, 764, 765, 766, 767, 768, 769, 770, 771, 772, 773, 774, 775, 776, 777, 778, 779, 780, 781, 782, 783, 784, 785, 786, 787, 788, 789, 790, 791, 792, 793, 794, 795, 796, 797, 798, 799, 800, 801, 802, 803, 804, 805, 806, 807, 808, 809, 810, 811, 812, 813, 814, 815, 816, 817, 818, 819, 820, 821, 822, 823, 824, 825, 826, 827, 828, 829, 830, 831, 832, 833, 834, 835, 836, 837, 838, 839, 840, 841, 842, 843, 844, 845, 846, 847, 848, 849, 850, 851, 852, 853, 854, 855, 856, 857, 858, 859, 860, 861, 862, 863, 864, 865, 866, 867, 868, 869, 870, 871, 872, 873, 874, 875, 876, 877, 878, 879, 880, 881, 882, 883, 884, 885, 886, 887, 888, 889, 890, 891, 892, 893, 894, 895, 896, 897, 898, 899, 900, 901, 902, 903, 904, 905, 906, 907, 908, 909, 910, 911, 912, 913, 914, 915, 916, 917, 918, 919, 920, 921, 922, 923, 924, 925, 926, 927, 928, 929, 930, 931, 932, 933, 934, 935, 936, 937, 938, 939, 940, 941, 942, 943, 944, 945, 946, 947, 948, 949, 950, 951, 952, 953, 954, 955, 956, 957, 958, 959, 960, 961, 962, 963, 964, 965, 966, 967, 968, 969, 970, 971, 972, 973, 974, 975, 976, 977, 978, 979, 980, 981, 982, 983, 984, 985, 986, 987, 988, 989, 990, 991, 992, 993, 994, 995, 996, 997, 998, 999, 1000</sup>	USA	Medical cover for people aged 65+ years; or under 65 years with certain disabilities; and people of any age with end-stage renal disease. Cover includes hospitalization, medical insurance, and prescription drugs. Most studies use a 5% random sample systematically selected using the same algorithm each year provided by the Centre for Medicare and Medicaid Services (CMS).
<b>Medicaid research files</b> <sup>27, 60, 86, 96, 133, 166, 262</sup>	USA	Joint federal and state funded program to provide low cost medical care for low-income people, families and children, pregnant women, the elderly, and people with disabilities. There are strict eligibility requirements that vary by state.
<b>Veterans Health Administration database</b> <sup>41, 65-74, 128</sup>	USA	Health data from 8.9 million American military veterans over a network of contracted providers across 179,134 facilities in 134 states and territories. Eligibility for coverage depends on the recipient having a service-related disability or being poor. The vast majority covered are male (95%).
<b>IMS HealthLink &amp; PharMetrics Integrated Outcomes database</b> <sup>61, 65-74, 273</sup>	USA	Integrated claims database of over 100 commercial insurers. Medical and pharmacy data linked at the individual level for 70 million covered people belonging to 64 national and regional managed care organisations since 1998.
<b>Commercial claims databases</b> <sup>69, 40, 25-27, 49, 124, 138, 173, 380, 392, 136, 399, 201, 218, 242, 283, 285, 287, 274</sup>	USA	Medical insurance and prescription claims datasets. Includes: Ingenix Research Database, HealthNet Claims Data California, Mutual of Omaha current trends, Independent Practice Association New York State, Protocare Sciences Managed Care database, AdvancePCS, Medco Health Solutions and HealthCore
<b>Canadian provincial health administrative databases</b> <sup>1, 78, 131, 106, 105, 136, 227</sup>	Canada	Health administrative data collected by the provinces in the delivery of universal coverage of health services in Canada. Data collection varies across the provinces but typically includes physician billing, hospital separations, prescription drug claims, emergency and ambulatory care, home care and rehabilitation data.
<b>Bureau of National Health Insurance Research Database</b> <sup>48, 96, 98, 102, 108, 223, 24, 97</sup>	Taiwan	The Bureau of National Health Insurance, Taiwan (BNHI) provides health coverage for 99.9% of the 23 million people in Taiwan (including immigrants). Information includes hospital inpatient claims, ambulatory care, and prescription drugs claims. Data subsets available for research include the longitudinal health insurance dataset – a randomly selected cohort of 1,073,891 subjects and all their claim data (data-files are available for cohort selected in years 2000, 2005 and 2010). Other data subsets include: dental, traditional Chinese medicine, cancer, diabetes, psychiatry, occupational disease, traffic accident, and rehabilitation.
<b>National Hospital Patient Register</b> <sup>14, 67, 137, 181, 182, 231</sup>	Denmark	Established in 1977, the National Hospital Patient Register (NPR) contains information on all inpatient hospital stays in Denmark. It has been linked universal from 2000 when the NPR became the method of funding hospitals.
Data Linkage systems		
<b>Western Australia Data Linkage System (WADLS)</b> <sup>7, 3, 53, 94, 107, 108, 207, 174-179, 213, 245</sup>	Australia	The WADLS consists of state-wide core de-identified linked datasets comprising hospital morbidity collection, emergency attendances, births, deaths and cancer registries. Plus linkages to other government datasets e.g. Main Roads Department. It covers a historical population of 3.7 million people over 30 years.
<b>Rochester Epidemiology Project (REP)</b> <sup>7, 3, 53, 94, 107, 108, 207</sup>	USA	The REP has linked medical records of all residents in Olmsted County, Minnesota, since 1975; including all patients of the Mayo Clinic, the Olmsted Medical Center, and other smaller medical practices. <sup>56</sup> By 2010 the project encompassed 6,259,333 person-years of follow-up for 502,820 individuals. <sup>56</sup>
<b>Oxford Record Linkage Study (ORLS)</b> <sup>91, 130, 131</sup>	UK	The ORLS comprises over 10 million records from a historical population of over five million people in the Oxford region and consists of computerized, irreversibly anonymized <sup>7</sup> abstracts of records of morbidity (hospital separations), births and deaths from 1963 to present date.
<b>Institute of Clinical and Population Sciences (ICPS), Ontario</b> <sup>3, 2, 2, 92-94, 225</sup>	Canada	The ICPS Data Repository consists of de-identified linked health datasets across most of the provincially funded health services since 1986 in Ontario for approximately 13 million people.

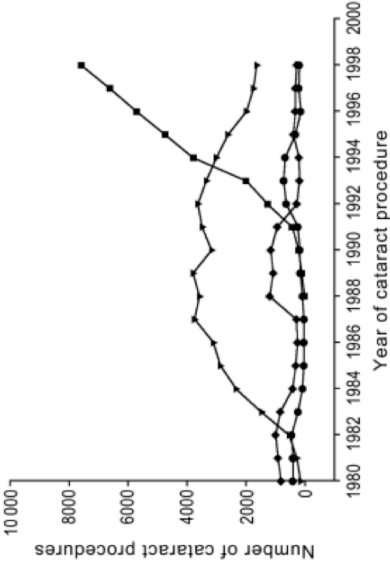
i.	<b>Unique matching (deterministic matching)</b> - data are linked according to unique identifiers e.g., health insurance number. This would be the most expeditious way to link data yet is limited since few datasets share a common identifier. In addition, due to recording errors this method may only identify 80-85% of true matches. <sup>79</sup>
ii.	<b>Fuzzy matching</b> - data are linked according to partial identifiers (usually multiple) e.g.; name, date of birth, address etc. This technique allows for a margin for error by linking records that are almost the same. The computer will either present a choice of matches to the user or will rely on a scoring system to confirm a match. This usually identifies 85-90% of true matches. <sup>79</sup>
iii.	<b>Probabilistic matching</b> - the decision regarding a match is made using decision rules that are built into a software package. These are based on the probability that two records are from different people given they have the same identifiers. The probabilities are then aggregated to form a score and a link is confirmed if a predefined threshold is reached. This typically identifies 95-99% of true matches with a 1-2% false positive rate. <sup>79,112,204</sup>

**Table 2 – Data linkage techniques.**

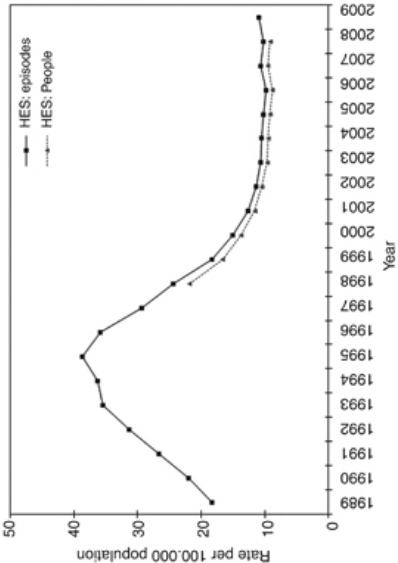




**Figure 1.** Dr Halbert Dunn (1896 - 1975)



**Figure 2a.** Trends in cataract procedure types (1980 to 1998). (•), Intracapsular; (▼), extracapsular; (■), phacoemulsification; (♦), other.



**Figure 2b.** Hospital admission rates per 100,000 population for trabeculectomy; English national data from 1989/90 to 2008/9 measured as episodes and people per year.

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## Appendix 6: Statements of contribution

To Whom It May Concern

I, Antony Clark, contributed data collation, analysis and manuscript preparation to the paper:

**Clark A, Ng JQ, Morlet N, Mahendran P, Tropiano E, Spilsbury K, Preen DB, Semmens JB. *Quality of life after postoperative endophthalmitis*. Clinical and Experimental Ophthalmology 2008; 36 (6): 526-531.**



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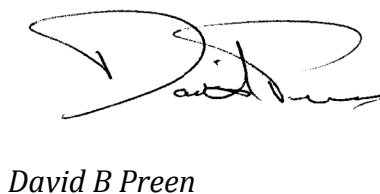
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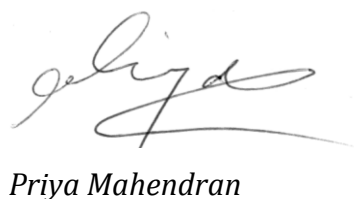
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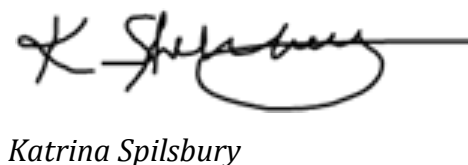
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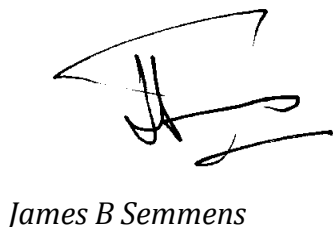
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Priya Mahendran



Katrina Spilsbury



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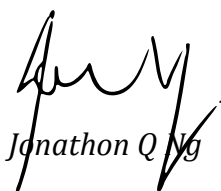
To Whom It May Concern

I, Antony Clark, contributed data collation, analysis and manuscript preparation to the paper:

**Clark A, Preen DB, Ng JQ, Semmens JB, Holman CDJ. Is Western Australia representative of other Australian States and Territories in terms of key socio-demographic and health economic indicators? Australian Health Review 2010; 34 (2): 210-215.**



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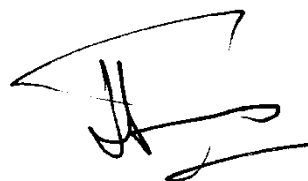
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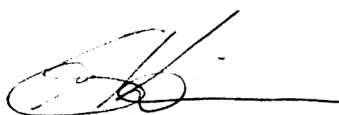
*Clark A, Morgan WH, Kain S, Farah H, Armstrong K, Preen DB, Semmens JB, Yu DY. **Diabetic retinopathy and the major causes of vision loss in Aboriginals from remote Western Australia.** Clinical and Experimental Ophthalmology 2010; 38: 475-482.*



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WH Morgan



Sam Kain

Hussein Farah

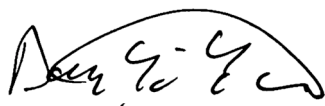


Kiele Armstrong

David B Preen



James B Semmens



Dao-Yi Yu

To Whom It May Concern

I, Antony Clark, contributed survey design & distribution, ethics application and assisted with data analysis and manuscript preparation to the papers:

*Yuen J, Clark A, Ng JQ, Morlet N, Keeffe J, Taylor HR, Preen DB. Further survey of Australian ophthalmologists' diabetic retinopathy management: did practice adhere to National Health and Medical Research Council guidelines? Clinical and Experimental Ophthalmology 2010; 38: 613-619.*

*Ting D, Ng JQ, Morlet N, Yuen J, Clark A, Taylor HR, Keeffe J, Preen DB. Diabetic retinopathy management by Australian optometrists. Clinical and Experimental Ophthalmology 2011; 39: 230-235.*

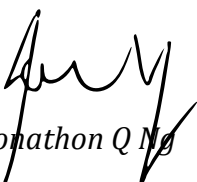
*Ting D, Ng JQ, Morlet N, Yuen J, Clark A, Taylor HR, Keeffe J, Preen DB. Diabetic retinopathy management by Australian GPs. Australian Family Physician 2011; 40: 233-238.*



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*Joshua Yuen*



*Jonathon Q Ng*

*Jill Keeffe*



*Hugh R Taylor*



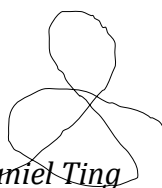
*David B Preen*



*James B Semmens*



*Nigel Morlet*



*Daniel Ting*

To Whom It May Concern

I, Antony Clark, contributed research design, ethics applications, data collection, analysis and manuscript preparation to the papers:

**Clark A, Morlet N, Ng JQ, Preen DB, Semmens JB. Whole population trends in complications of cataract surgery over 22 years in Western Australia. Ophthalmology 2011; 118 (6). 1055-61**

**Clark A, Morlet N, Ng JQ, Preen DB, Semmens JB. Retinal Detachment after phacoemulsification. Archives of Ophthalmology 2012; 130(7):882-8.**

**Clark A, Morlet N, Ng JQ, Preen DB, Semmens JB. Trends and outcomes of anterior vitrectomy after cataract surgery. Acta Ophthalmologica 2014.**



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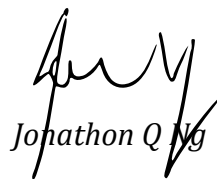
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I, Antony Clark, contributed to research design, ethics application, linked data applications, primary data collection, and provided input on data analysis and manuscript preparation to the paper:

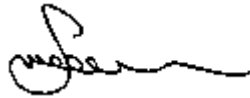
*Kemp A, Preen DB, Morlet N, **Clark, A**, McAllister IL, Briffa T, Sanfilippo FM, Ng JQ, McKnight C, Reynolds W, Gilles MC. **Myocardial Infarction After Intravitreal Vascular Endothelial Growth Factor Inhibitors: A Whole Population Study.** Retina 2013; 2013; 33, 920-927.*



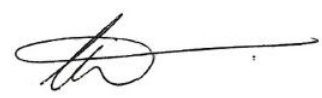
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Anna Kemp



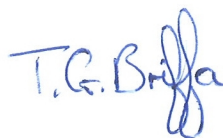
Ian L McAllister



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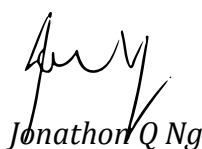
Nigel Morlet



Frank M Sanfillipo



Mark Gillies



Jonathon Q Ng

To Whom It May Concern

I, Antony Clark, contributed assistance in clinical validation clinics and, data analysis and interpretation, and manuscript preparation to the papers:

*Crewe J, Morgan WH, Morlet N, Spilsbury K, Mukhtar SA, **Clark A**, Ng JQ, Crowley M, Semmens JB. **Assessing the diagnostic validity of a blind register** Clinical and Experimental Ophthalmology 2011; 39(6):494-500.*

*Crewe J, Morgan WH, Morlet N, **Clark A**, Lam G, Parsons R, Mukhtar A, Ng J, Crowley M, Semmens J. **Prevalence of blindness in Western Australia: a population study using capture and recapture techniques.** British Journal of Ophthalmology 2011; 96(4):478-481.*

*Crewe J, Morlet N, Morgan WH, Spilsbury K, Mukhtar SA, **Clark A**, Ng JQ, Crowley M, Semmens JB. **Quality of life of the most severely vision-impaired.** Clinical and Experimental Ophthalmology 2011; 39(4):336-343.*

*Crewe, J. M., Lam, G., **Clark, A.**, Spilsbury, K., Mukhtar, A. S., Morlet, N., Morgan, W. H., Crowley, M. and Semmens, J. B. **Hospitalization rates of children who are blind.** Clinical and Experimental Ophthalmology 2013; 41(8):773-778.*

*Crewe JM, Morlet N, Morgan WH, Spilsbury K, Mukhtar AS, **Clark A**, Semmens JB. **Mortality and hospital morbidity of working-age blind.** British Journal of Ophthalmology 2013; 97(12):1579-1585.*



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Julie Crewe



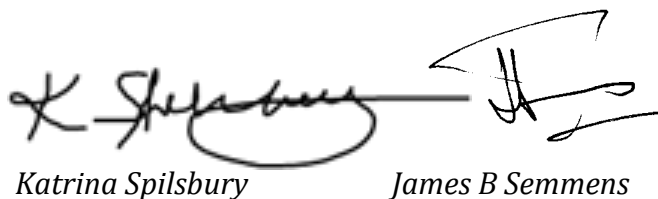
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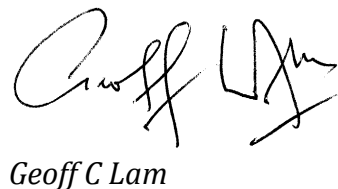
William H Morgan



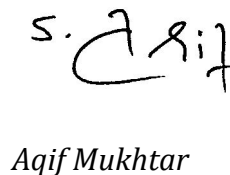
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